

DISABILITY IN HEALTH IMPACT ASSESSMENT

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February 2012

ABSTRACT

People with disabilities are a ‘disadvantaged’ group, not only due to their impairment, but also due to the formal and informal institutional inertia that they contend with in Western Societies. This disadvantage has been recognised and acknowledged in the social model of disability. This model understands that disability is a social construction placed on people with impairments.

The Health Impact Assessment (HIA) is a tool which identifies inequities in policy, and is potentially a useful tool to aid the response of policy makers to the needs of people with disabilities. Arguably, the New Zealand HIA guidelines reflect the underlying principles of the social model of disability.

Using a mixed methods research strategy, this thesis sets out to understand in a global context using a top-down quantitative analysis, to what extent the New Zealand HIA guidelines which acknowledge the social model of disability are translated into practice. It then subsequently investigates from a bottom-up qualitative perspective, what factors influence this relationship. It is argued in this thesis that there are barriers to translating the rhetoric about people with disabilities found in the HIA guidelines into practice. Three sets of inter-related barriers identified include attitudinal barriers to people with disabilities, generic HIA barriers, and barriers related to the feminist interpretation of the construction of disability.

In this thesis, the research findings conclude that it is difficult to operationalise the disability awareness present in the HIA guidelines due to barriers which are related to the ‘othering’ of people with disabilities. This is discussed in relation to feminist analyses of the construction of people with disabilities, and it needs to be addressed by wider societal reforms. The thesis makes the recommendation that a national awareness-raising campaign about people with disabilities be undertaken in New Zealand in an attempt to rectify this situation.

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ACKNOWLEDGEMENTS

Similar to many of the accomplishments that I have achieved as a person with a disability, this thesis has had an input from many people.

First and foremost I would like to thank my Mum and Dad who have, like with every other challenge I have attempted, given me their full and perpetual support. My Mum has ensured that I have been kept well fed throughout the process, and my Dad has never stopped believing that my writing will reach a ‘thesis-standard’!

I also owe much gratitude to my research assistant Emily Hewitt. Emily has been my eyes in so many contexts, but also an incredible support keeping me positive when times have been hard. Without Emily, there is no way that this thesis could have been completed and though my name will be at the bottom of this work, Emily can also take pride in what she has helped produce.

I would like to thank the staff at the Disability Resource Services especially Steve and Sam, at the University of Canterbury, who have made it possible for me to get around the socially imposed barriers in education that I face as a person with a disability. I have no doubt that this thesis is a testimony to how well they do their work, and I can only hope that all other people attempting a challenge such as this are also supported by such an innovative team.

My academic supervision team (Senior Supervisor Dr Annabel Taylor and Associate Supervisors Dr. Anne Scott and Professor Ken Daniels) have also been an integral part of this work. Their feedback and expertise in their various fields has proven a real benefit to my ability to produce a piece of work at this standard.

All my friends and family, your support and love has not been unnoticed. And I am grateful that I have not had to travel this journey alone. I would also like to express special thanks to my colleagues who contend with a world made exclusively for fully able people. You have all opened my eyes, and brought a practical perspective to this research. I sincerely hope that this thesis will make life for us all a bit easier, and our jobs as ‘disability awareness trainers’ will cease to exist.

CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

This chapter defines the research problem that this thesis seeks to investigate. The research questions that have been formulated to provide insight into this phenomenon will be presented. A broad summary is then given of the chapter organisation and the methodology used to answer these questions.

CHAPTER OVERVIEW

- Section 1.2 – this presents my personal background in connection to the thesis topic.
- Section 1.3 – provides the underlying rationale for this research.
- Section 1.4 – using the backdrop explains the research problem, and defines the research questions to provide insight into how the question will be investigated.
- Section 1.5 – presents the research methodology that will be used to answer the research questions.
- Section 1.6 – will provide an outline of the organisation of how the research will be presented.

1.2 PERSONAL BACKGROUND

In the winter of the year 2000, I contracted a virus which caused me to drift into a long period of coma, and which left me with a traumatic brain injury that caused me to lose all learned human functions. Following my re-entry into consciousness, I underwent rehabilitation which allowed me to regain all faculties except sight and balance. These are now impairments that I live with on a day to day basis.

Disability is a part of my life which I am vocal about as I feel it is not very well understood by society. However, the barriers that I face, due to my high self-esteem, are relatively few compared with my counterparts who may have had to contend with the societal stigma of disability all their lives. When policies or procedures are enacted which are inequitable and

disadvantage people with disabilities, I feel deep empathy and am passionate for change. Through informal contacts and conversations with other disabled people, I have come to appreciate that many of these barriers are a function of central and local government policies that govern these peoples' lives and the consequent discrimination that these policies create, which often lacks any rational basis.

During my honours year of study (2009), I took papers in public health which introduced me to the topic of 'Health Impact Assessment'. Health Impact Assessment (henceforth HIA) is a policy tool used to evaluate health and related social impacts of policies, particularly on disadvantaged sectors of society, including the disabled. I wondered if the HIA was really achieving its potential to identify the barriers that people with disabilities faced. This topic was an obvious choice of research for me to undertake for my thesis, and my hope is that findings of this research will potentially lead to an increase in the health and wellbeing of people with disabilities in New Zealand.

1.3 RESEARCH PROBLEM

Globally, the number of people with disabilities is estimated to be over 500 million people (Costaneda & Peters, 2000). Historically, people with disabilities have been marginalized by the majority in many societies (Barnes, Mercer & Shakespeare, 1999; Oliver, 1998). They are often marginalized politically, socially and economically (Goggin & Newell, 2005; Beatson, 2001). People with disabilities are perceived as a 'burden on society' (Oliver, 1998).

One in five people in New Zealand report having a long term disability (Office for Disability Issues (ODI), 2001). People with disabilities are widely understood to constitute a disadvantaged sector of the New Zealand society in a number of different respects including employment, housing and health (ODI, 2001; Goggin & Newell, 2005). The New Zealand Government has recognised this inequity and in effort to address this issue, it has adopted the *New Zealand Disability Strategy* (ODI, 2001). The strategy is a New Zealand context of the social model of disability, in contrast with the medical model. The medical model of disability is based on the assumption that disability is an individual affliction and that people with disabilities should modify their behaviours to fit in with mainstream society. Advocates of the more contemporary

social model of disability argue that disability is a social construction, and the health of people with disabilities is governed by both formal and informal societal institutions. Based on this model and approach, the *Disability Strategy* makes 15 broad recommendations to promote a fair society for people with disabilities in New Zealand.

Good health is a major objective of many governments. Good health is defined broadly as encompassing the physical, mental, spiritual, and psychological aspects of health and wellbeing (World Health Organisation (WHO), 1984). The Health Impact Assessment draws on this very broad ‘social’ model of health (Germov, 2009) to address the social, environmental and physical determinants of health in policy and related projects.

HIA is defined as a “formal way to predict the potential effects of policies on health, wellbeing and equity” (Lock, 2000). The underlying intent of HIA as a policy tool is to avoid, remedy or mitigate adverse impacts of government policies on disadvantaged sectors of society. HIA procedures are based on the recognition that the health status of people and communities is not homogeneous and the status is greatly influenced by inter-related factors beyond the conventional purview of the health sector (Lock, 2000). HIA can promote good health by diagnosing and making recommendations to a proposed development or changes to an established development which are identified by the community who utilise its services.

The New Zealand Government has recently adopted Health Impact Assessment (HIA) procedures as a means of assessing the impact of various policies on health and wellbeing in New Zealand. The New Zealand *A Guide to Health Impact Assessment: A Policy Tool for New Zealand* (PHAC, 2005) is a document that contextualizes HIA to the New Zealand experience, and makes reference to the social model of disability. From the perspective of people with disabilities, HIA can thus help to identify and address inequalities in health status of this group of people, which are a result of central and local government policies. Arguably, this tool has the potential to ensure that people with disabilities, who already belong to a disadvantaged sector due to their impairments, are not further disadvantaged by the policies by which they are governed.

The HIA procedures set out the HIA procedural methodology and related considerations that should be taken into account when undertaking an HIA. More importantly, the New Zealand

HIA procedures, in significant contrast to other international guides, emphasises the recognition of needs of people with disabilities when undertaking an HIA assessment and takes cognizance of the social model of disability which underpins the *New Zealand Disability Strategy* (ODI, 2001). It could then be expected that the outcome of this policy would mean that disability assessment would be a significant facet of HIA practice in New Zealand. The overall aim of this study is to critically assess to what extent this statement is true. This is achieved by investigating the potential barriers which could prevent the translation of disability policy in HIA into policy practice in New Zealand, and what factors influence these barriers.

RESEARCH QUESTIONS

I defined two research questions to address the above research aim, as follows:

1. What is the relationship between policy and practice in relation to disability awareness in the HIA procedures in New Zealand?
2. What are the factors influencing this relationship?

This thesis will investigate these two questions, and conclude with a deeper insight into whether the acknowledgement of people with disabilities in HIA policy and practice is a reality or merely an obligatory rhetoric, and suggest reasons for this relationship.

1.4 RESEARCH METHODOLOGY

The research methodology is discussed more comprehensively in chapter three. This section will provide an introductory overview of the methodology.

Initially, a literature review was conducted to help identify and define the research problem and to formulate the research methodology. I read international and New Zealand literature from a number of social science disciplines pertaining to disability, HIA and the relationship between these two subjects.

I developed a two-pronged research strategy to address the first research question. I undertook a content analysis of national HIA guidelines from a selection of four countries: England,

Scotland, Australia and New Zealand. These countries share basic common characteristics as Anglophonic societies. The intent of this content analysis exercise was to ascertain to what extent the respective national HIA policy guidelines took cognizance of needs of the disabled in England, Scotland and Australia compared with New Zealand. This set the broader context for the study.

To complement the content analysis of recent national HIA policy documents, I then did a content analysis of a range of recent HIA reports from each country. The intent of this top-down analysis of HIA policy implementation was to enable me to assess where New Zealand stood in relation to addressing needs of the disabled in HIA practice in England, Scotland and Australia.

The above two-pronged analysis to address the first research question led to the conclusion that, compared with other Anglophonic societies, New Zealand national HIA policies demonstrated a much more comprehensive understanding of needs of people with disabilities in terms of the recognition of the social model of disability and its important principle of inclusion. However, when comparing the disability acknowledgement in completed HIA practice reports, the same level of consideration and inclusion of people with disabilities was not observed.

This finding led to the second research question: What factors can explain this policy/practice gap? I addressed this question by revisiting the literature on policy implementation and HIA, which concluded with three potential explanations. These barriers were ‘Generic HIA barriers’, ‘Unconscious attitudinal barriers faced by people with disabilities’, or were explained by ‘Feminist interpretations of the constructions of disability’. The most robust way that I could verify any of these explanations found in the literature in my own research was by conducting a bottom-up approach to policy analysis via interviews with six HIA experts, both policy makers and practitioners. It was felt that they would have the best insights into HIA practice relating to disability in New Zealand. I refer to the approach I undertook in this study as a mix of the top-down and bottom-up perspectives to understand policy implementation.

Five of the six in-depth interviews were analysed thematically for any barriers that were identified in the practice of disability in HIA procedures. This analysis revealed that two of the three sets of barriers defined in the literature were verified. The ‘Unconscious attitudinal barriers towards

people with disabilities’ could be defined and the ‘Generic barriers to HIA’ were identified. However, the barriers related to the ‘feminist interpretations of the construction of disability’ were not identified in the interviews. It is argued that these barriers underpin all the other defined barriers, and could be defined as the meta-level of the problem. The research concluded that the barriers analysed within the ‘feminist interpretations of the construction of disability’, which constituted institutional discrimination and focused largely on the phenomena of ‘otherness’ presented in many forms, explained the reasons that the intent of the social model of disability embedded in national HIA procedures, was not being practiced.

To conclude, it is argued that in accord with the intent of the social model of disability, these barriers can only be addressed with radical institutional changes in New Zealand society.

1.5 ORGANISATION OF THE STUDY

The thesis is structured as follows:

Chapter two discusses HIA and disability, and HIA in relation to disability literature reviewed to set the wider conceptual context for the study and make the study more comprehensible to the reader.

Chapter three explains the research methodology used, which consists of a mixed-methods approach using both a quantitative top-down content analysis of disability inclusion in guiding HIA rhetoric, and a qualitative, bottom-up approach to policy analysis. The latter involved interviews with five HIA experts to better understand the New Zealand context to the barriers to the recognition of people with disabilities in the HIA process.

Chapter four assesses to what extent disability is recognised in national HIA policy in New Zealand and compares and contrasts this with other similar Anglophonic countries using a content analysis of different HIA policy guidelines.

Chapter five is based on a consideration of disability in HIA reports from the countries whose guidelines were analysed in the previous chapter. This analysis is a top-down quantitative policy analysis of completed HIA reports.

Chapter six revisits international and New Zealand literature on policy implementation of HIA and related social policy sectors to understand possible reasons that may impair the translation of policy to practice.

Against the backdrop of the above understanding, chapter seven investigates reasons for the policy implementation gap in New Zealand's HIA sector using a bottom-up approach to policy analysis via qualitative interviews with key players in the HIA process in New Zealand. These findings are analysed thematically in relation to the literature reviewed in the last chapter, before the argument of a potential meta-analysis, which allows a conclusion to be drawn.

Chapter eight summarises the study, draws some conclusions based on the research findings, and reviews the policy significance of the thesis findings from HIA theory and practice perspectives. Finally, recommendations for future research of ways to address this problem are presented.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, I will review key themes found in recent HIA and disability literature. I will discuss these issues in three consecutive sections: HIA (Section 2.2); disability (Section 2.3) and the relationship between HIA and disability (Section 2.4). This review will provide the conceptual context to the research that follows.

CHAPTER OVERVIEW

Section 2.2 presents an overview of the policy tool: Health Impact Assessment (HIA). This section is organised as follows:

- Section 2.2.1 The wider equity and bioethical principles that underpin the HIA;
- Section 2.2.2 Development of HIA as a policy tool;
- Section 2.2.3 Objectives of HIA;
- Section 2.2.4 Varying international interpretations of HIA;
- Section 2.2.5 Adoption of HIA practices in New Zealand against the backdrop of the previous sub-section;
- Section 2.2.6 The international and New Zealand literature on barriers to HIA practice.

Section 2.3 reviews literature to aid our understanding of people with disabilities. This section is organised as follows:

- Section 2.3.1 A generic history of disability in the Western World;
- Section 2.3.2 Legislation underpinning disability rights in New Zealand, and the present state of this legislation;
- Section 2.3.3 The two most contested views of disability which are pertinent to every person with a disability who lives in society;
- Section 2.3.4 The National Disability Strategy which has been written to endorse a more equitable world for people with disabilities who live in New Zealand;

- Section 2.3.5 The most significant barriers faced by people with disabilities which are largely a product of societal constructions.

Section 2.4 The connections between disability and Health Impact Assessment. This section is structured as follows:

- Section 2.4.1 The Determinants of Health as defined by the Health Impact Assessment, which are analogous to the barriers that people with disabilities face;
- Section 2.4.2 The literature which brings together disability and Health Impact Assessment.

Section 2.5 makes some concluding statements about the arguments that have been presented in this literature review.

2.2 OVERVIEW OF HEALTH IMPACT ASSESSMENT

HIA is a policy tool that can potentially alert policy makers to the inequalities that their policies have on disadvantaged parts of the population (including people with disabilities), so they can remedy or mitigate any negative effects on these groups before the policy is enacted.

2.2.1 *PHILOSOPHICAL UNDERPINNINGS OF HIA AS A POLICY TOOL*

Equity and bioethical principles are the fundamental philosophical underpinnings of HIA, as discussed below.

2.2.1.1 Equity

Equity, as defined by the World Health Organisation (WHO), is ‘the avoidance of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically’ (WHO, n/d). The WHO also defines equity in health as when ‘people’s needs guide the opportunity for well-being’ (WHO, n/d).

Health inequalities occur as a function of differences between people who have different social and economic circumstances, or as the result of different lifestyle choices. Inequities occur when

people have different opportunities for wellbeing. A common characteristic of groups who do not show a good level of wellbeing such as marginalised ethnic or racial groups, poor or marginalised persons, women, or people with disabilities, is that they do not have social, political or economic power (WHO, n/d).

As access to a standard of living adequate for good health is a fundamental human right for signatories of the Universal Declaration of Human Rights (1948), equity must be displayed in all parts of life which can affect health and wellbeing.

HIA attempts to promote equity by understanding the ways that policies which guide the determinants of health affect the health and wellbeing of groups in the population who already face disadvantages which are based on biological circumstances.

2.2.1.2 Bioethical Principles

Many authors, including Beauchamp and Childress (2009), have defined four principles that guide ethical considerations when undertaking an exploration of any medical venture such as the HIA:

- **Autonomy:** Autonomy specifies that we should decide our own fate. It emphasises the personal responsibility for our own lives and therefore the right to choose and make our own decisions and dictate what is done to us. All medical procedures that we undergo need to have been personally decided on, and the choice of whether they are carried out is ours alone. In HIA, the consultation process which allows members of the community to express their own personal views is deemed as an integral step of the process.
- **Nonmaleficence:** Nonmaleficence is an ethical principal that originates from the ancient Hippocratic Oath: 'First of all, do no harm'. In medical terms, this means that any intervention must not intentionally cause harm. The Health Impact Assessments endorse this principle.
- **Beneficence:** This principle highlights that we have a positive obligation to advance the healthcare interests and welfare of others, to assist others in their choices to live the healthiest life they can, also known as 'doing good'. This is arguably the main aim of the HIA; to increase the welfare and good of the population.

- **Justice:** Justice may be described as the allocation of healthcare resources according to a just standard. This principle acknowledges that health is not homogeneous within the population. There are two basic types of justice. Comparative justice involves balancing the competing claims of people for the same health care resources and is necessary because health funding is not unlimited and there is a need to prioritise resources. In comparative justice what one receives is determined by one's particular condition and needs. Distributive justice, on the other hand, determines the distribution of health care resources by a standard that is independent of the claims of a particular person. HIA operates on the understanding of comparative justice and strives to make society more equitable (Degrazia & Mappes, 2005; Beauchamp & Childress, 2009).

Health Impact Assessment is a tool which emphasises all bioethical principles, especially the principle of justice, as it tries to identify and remedy inequalities in health that are a function of the determinants of health. This tool could potentially highlight inequalities in policies, and alert policy makers to create and implement policies that do not negatively affect people with disabilities if they view this sector as a valuable part of society.

2.2.2 THE DEVELOPMENT OF HIA AS A POLICY TOOL

Impact assessment is not a new concept. It has been used mostly in the Environmental field (EIA – Environmental Impact Assessment) to understand the impacts of human procedures and policies on the environment (Birley, 2003; Scott-Samuel, 1998; WHO Regional Office for Europe, 1999), and in the social arena (SIA – Social Impact Assessment) (Birley, 2003).

Public Health is a discipline that straddles the bounds of the understanding of health as both a social and medical construct. As the understanding increases that health is determined by a combination of economic, social, psychological and political factors, and not purely a product of biological factors, the need for a tool which can assess the effect of all these factors increases (Lock, 2000; Scott-Samuel, 1998). Lock (2000) explains that the development of the HIA is an extension of Public Health practice that has been in existence since Victorian times when John Snow first explained that the reason for cholera outbreaks in the city of London was due to the unhealthy state of the city's water supply (Vinten-Johansen et al., 2003).

Public health has more recently developed into the 'New Public Health' model (Baum, 2008). The 'new public health' is focused on empowering communities and addressing the social and other determinants of health. Part of this involves the creation of healthy public policy. Healthy public policy is a health promotion action which is defined by the Ottawa Charter of Health Promotion developed in 1986 (Lock, 2000). A healthy public policy is a policy that has a positive impact on the individuals and communities it affects (Kemmer, 2001).

Community and Public Health of the Christchurch District Health Board is a present day example of the recognition of the importance of public health, and healthy public policy. The Department of Public Health in New Zealand aims to increase the health of populations and communities, increase Māori health status, and reduce inequalities in health status between groups (MOH, n/d).

This understanding has led to a number of proposals to integrate human health into Environmental Impact Assessment (Birley, 2003). Birley has suggested that a possible advantage of integration is 'synergy', as the efforts of both an EIA and SIA are combined. A possible disadvantage is 'impractical complexity', as there are many factors determining health, which are often hard to isolate where a straight and consistent causal link is hard to see (Birley, 2003). Many international charters on health have defined the need to be able to assess the effects of policies, programs and projects on health. The Gothenburg consensus paper (WHO Regional Office for Europe, 1999), the Jakarta Declaration, the United Kingdom policy paper 'Saving Lives, Our Healthier Nation' (Lock, 2000), and Article 52 of the European Union Treaty (Birley, 2003) all define this as a goal. The use of an integrated EIA/SIA would enable the goals emphasised in these charters to be met, and would alert decision-makers to the effects of their policies on the health of the population, allowing them to maximise the positive effects of policy by minimising the negative effects (WHO Regional Office for Europe, 1999). This tool has come about in the discipline of public health in the form of the Health Impact Assessment.

2.2.3 OBJECTIVES OF HIA

Health Impact Assessment is a population-based tool endorsed by the World Health Organisation (WHO), and developed by the New Zealand Public Health Advisory Committee (PHAC). It assesses the health effects of any policy, project or program on a population from a wide range of determinants (Kreiger et al., 2003; Lock, 2000; Joffe & Mindell, 2002; WHO, n/d).

By diagnosing the potential effects of a policy, policy makers are better equipped to build 'healthy public policy' (Lock, 2000; Kreiger et al., 2003; WHO, n/d). The HIA straddles between the medical and social definitions of health, understanding health as an outcome of holistic determinants. It can potentially highlight inequalities that different sectors of the population face, which are a function of policy and thus, can allow policy makers to remedy their policies. This means policies can be created that maximise the status of all people's health by minimising the adverse effects of policy on the determinants of health (Lock, 2000). Among these determinants are income, education, physical environment, social support, genetics, access to health services and gender (WHO, n/d). The most significant determinant of health in Aotearoa/New Zealand is ethnicity, with Māori being under-represented in every determinant of health (Robson & Harris, 2008). The potential effect that HIA can have on the health of a population is substantial. This is because the tool works at a 'whole of population' level, aiming to assess the impacts of policy, and make government aware, so they can amend policies to minimise the adverse impacts on all groups in the population (Lock, 2000; Wise, Harris, Harris-Roxas and Harris, 2009).

HIA is based on four main values:

- Democracy – Allowing people to participate in the development and implementation of projects, policies or programmes that may impact their lives.
- Equity – HIA assesses the distribution of impacts from a proposal on the whole population with particular reference to how the proposal will affect vulnerable people (in terms of age, gender, ethnic background, or socio-economic status).
- “Sustainable development – That both short and long term impacts are considered along with the obvious and less obvious impacts.
- “Ethical use of evidence – The best available qualitative and quantitative evidence must be identified and used in the assessment, using the best possible methods” (WHO, n/d).

The basis of HIA is to try and make predictions about the outcomes of a policy on human health. This is based on the exposures, and the intensity of the exposures, using evidence from a scoping process (WHO, n/d). HIA involves intersectoral collaboration of many different stakeholders as the determinants of health are influenced by many varied sectors beyond the health sector (WHO, n/d; Kreiger et al., 2003). It focuses on the distribution of effects between different subgroups in a population, and predictions and recommendations can be made in

relation to how specific ‘vulnerable groups’ will be affected by a policy (WHO, n/d; Douglas & Scott-Samuel, 2009). Once this information is known, decision-makers have evidence-based recommendations as a starting point for their decisions, and policies or programmes can be changed in order that the negative effects of the policy on the populations are ameliorated. Lastly, HIA promotes the monitoring, evaluation and follow up of the HIA methodology to ensure that the outcomes of decisions made are beneficial to the population (WHO, n/d; Lock, 2000).

2.2.4 VARYING INTERNATIONAL INTERPRETATIONS OF HIA

In the developed World, the uptake of HIA is gradually gaining popularity when policies are being developed (Birley, 2003). However, many different models of this tool exist. Countries using this tool have their own specific contextualised interpretation of the HIA and hence unique procedures. Below is a small example of some of these models of HIA as they are utilised in different countries in the developed world.¹

Country/Region	Description
North America	Specific guidelines to HIA have been developed around discussion of the North American context of the quality, standards and values defined in all HIA models.
Wales	The Welsh version of HIA places special emphasis on the public participation aspect in reaching a positive outcome of policies, programmes, and projects on people’s health.
Australia	This practical Guide aims to provide an approach to HIA in Australia based on the findings of research conducted in New South Wales.

¹Retrieved From: North America: http://www.humanimpact.org/HIA_PracticeStandards.pdf; Wales: <http://www.wales.nhs.uk/sites3/home.cfm?OrgID=522>; Australia: <http://www.hiaconnect.edu.au/>; Northern Ireland: <http://www.publichealth.ie/hia>; Canada: <http://www.apho.org.uk/resource/item.aspx?RID=63462>; Sweden, World Bank, European Commission, European Policy: <http://www.apho.org.uk/>

Northern Ireland	<p>The HIA Guide is part of an integrated guide to conducting a range of policy proofing processes including:</p> <ul style="list-style-type: none"> • Equality Impact Assessment • Rural Proof • HIA and EIA
Sweden	This general guide pays special attention to Social and Environmental Sustainability.
Canada	The Canadian Handbook on Health Impact Assessment gives a guide for HIA in the context of issues that are pertinent in Canada.
World Bank	This guide applies to the expansion of existing facilities and projects and the development of new projects and new locations where the World Bank operates.
European Commission	The European Commission has written a guide for its staff to follow when undertaking the task of policy formation. Steps are defined when undertaking HIA, as well as procedural rules for planning, consultation, reporting and dissemination for HIA findings.
European Policy	This guide has been developed to assess the impact of European Union Policy on the population of member states.

There are many interpretations of HIA which have different aims and objectives, as demonstrated above. However, the research presented in this thesis relates to the New Zealand version of the HIA, *A Guide to Health Impact Assessment: A Policy Tool for New Zealand* (PHAC, 2005).

2.2.5 ADOPTION OF HIA IN NEW ZEALAND

In recent decades, New Zealand has been largely concerned with the health of its environment. Any performed Impact Assessments were upon the state of the environment (Morgan, 2008).

Health has been most commonly understood in New Zealand as ‘the absence of disease from biological pathogens, rather than ‘the effects of policies from many sectors on the wellbeing of a population’ (Morgan, 2008). This biomedical understanding of health was further endorsed with

the introduction of the Resource Management Act in 1991, which made regulations on the use and health of resources in New Zealand. It made health largely a protection issue, and made a requirement to perform an Environmental Impact Assessment before undertaking major developments as a means of control (Signal & Durham, 2000; Morgan, 2001).

In 1995, Health Impact Assessment was introduced into New Zealand through the Public Health Advisory Committee's Guide to HIA. This guide focused on HIA only in relation to environmental issues and was concerned largely with assessing risks of exposure to toxic substances. This was then followed closely by a guide to risk assessment. This guide gave a technical overview of risk-based HIA. Together, these two guides further implemented how 'Impact Assessment' should be understood at an environmental level (Morgan, 2008).

More recently, the National Health Committee (NHC) has understood the potential for the Health Impact Assessment to be used to identify inequalities in the population, which are a function of policy. This document, *The New Zealand Health Strategy* (2000), outlines the need to address the determinants of health, and understand the valuable intersectoral contribution that different sectors play in affecting people's health (Morgan, 2008). This 'social determinants' model of health is becoming more widely understood as the HIA gains popularity both in New Zealand and internationally (Morgan, 2001; Signal & Durham, 2000). This may decrease inequalities in society as different sectors of government understand the contribution of their policies to the health of the population.

In New Zealand, the policy context is a relatively simple one. As is it a unitary government, only one level of governance is involved with health, and all other policy making. All government departments prescribe to one model of HIA, and this is performed by a trained set of HIA experts in the government-run HIA Support Unit (Langford, 2005). At present, the take up of HIA by local government is higher than that of central government (Pers com, Barbara Langford, August 2010; Pers com, Louise Thornely, September 2010).

The New Zealand HIA Guidelines take a specific focus on equity (Pers com, Barbara Langford, August, 2010; MOH, 2004). This means that all HIAs performed should reflect a special understanding of the barriers faced by disadvantaged groups and the impacts of a policy, for example on old people, children, families with low socio-economic status, ethnic minorities, and people with disabilities (MOH, 2004). A specific tool has been included in the guidelines to

ensure this assessment, known as the Equity Lens. As health is not experienced uniformly within a population and there are specific groups who experience inequities in health due to the way a policy, programme or service affects them (Lock, 2000; Kreiger et al., 2003), the Equity Lens is a tool that has been developed to identify these inequalities. It enables equality assessment of policies, programmes, or services based on the populations who utilise them. These assessments then allow those who have made the policy, programme or service to strengthen it, and avoid the inequitable ramifications.

The Equity Lens consists of ten questions that enable assessment of a policy, programme or project for its current or future implications of equal health for different groups. The tool covers four stages of policy, programme, or project development:

- Understanding health inequalities;
- Designing interventions to reduce inequalities;
- Reviewing and refining interventions;
- Evaluating the impacts and outcomes of interventions (See Appendix C).

Thus, the Equity Lens is an important part of the New Zealand HIA guidelines and can be used to understand the ways that policies affect people with disabilities.

An integral part of the implementation of the HIA tool is the obligations of the Crown to Māori, under the Treaty of Waitangi. This treaty binds the Crown to ensure partnership and participation of Māori at all stages of policy development (Signal & Durham, 2000).

Anecdotal evidence may point to changes since the appointment of the new National Government in 2008. There have been several changes to the importance and value placed on 'prevention' ministries, such as the Department of Public Health. The Regional Public Health Unit in Christchurch has been downsized, and it can only be assumed that the value placed on the HIA tool has also decreased (Personal Communication, Margaret Earle, (POSITION) February 2011). If this is true, it is a disappointing outcome as HIA has the potential to make a beneficial contribution to the health of New Zealand society.

2.2.6 BARRIERS TO HIA

As discussed below, there are many barriers cited in both the international and New Zealand literature defining the limitations of using HIA as an effective tool to assess the health impact of policies on populations, and its value as a tool to be embedded in policy is questionable.

There are also more specific reasons for the limitations of the value of HIA, which are a deterrent to governments adopting HIA. These result in limited usage of the tool, and in themselves are reasons that the benefits of HIA are not obvious in some countries.

2.2.6.1 Barriers cited in the international literature

There is much international literature about the limitations to HIA, as discussed here. Metcalfe and Higgins (2009) feel that government support for HIA is an integral part of its ability to work. The WHO (n/d) also agree that political limitations maybe the reason that HIA cannot reach its full potential in some countries. Wismar, Ernst, Blau, Figuras/WHO (2007), along with Scott-Samuel and O’Keefe (2007), agree that often a political agenda is too narrow to think about ‘health’, and more likely to attend to ‘sickness’ as opposed to ‘protection from sickness’. Lack of resourcing by governments is another reason that has been cited to explain the barriers facing HIA (Mannheimer et al., 2007; Kreiger, 2003; Lester, Griffiths, Low & Smith, 2003; Metcalfe & Higgins, 2009; Scott-Samuel, 1998). Attitudinal barriers also exist, preventing the full scope of HIA from being realised. Both Mannheimer et al. (2010) and Morgan (2009) in his letter to the editor feel that people still focus on the traditional healthcare model of linear causal relationships to describe ill health, and do not see the benefit of the holistic determinants in causing a reduced wellbeing that are taken into account by the HIA. Chilaka (2010) feels that some people do not understand HIA as a policy tool, and Ali, O’Callaghan, Middleton and Little (2003) explain that the benefits of HIA are sometimes hard to see as they are long term and may not produce a quick result, and therefore the motivation for the adoption of HIA is hindered.

There are many factors which debilitate the effectiveness of HIA as a policy tool. Some of these are summarised below.

Lack of intersectoral work is a major barrier to HIA. An integral part of HIA is that a wide range of stakeholders with different expertise and knowledge can contribute to the outcomes reached in the HIA. This has high importance, as the aim of the HIA is to understand health holistically

and make recommendations that meet the needs of all populations affected by the policy. A lack of intersectoral work has been explained in many contexts in many papers, right from community, to business, to HIA practitioner involvement (Mannheimer et al., 2010; Ali et al., 2009; Lester & Temple, 2004; Douglas, Conway, Gorman, Gavin & Hanlon, 2001; Krieger et al., 2003; Scott-Samuel & O'Keefe, 2007; Parry & Stevens, 2001; Metcalfe & Higgins, 2009; Scott-Samuel & Douglas, 2001; Scott-Samuel, 1996). Both Quigley and Taylor (2003) and Parry and Stevens (2001) have cited in their papers the lack of evaluation as a reason for the HIA lacking in value. HIA is a process whose decisions need continual reassessment until the needs of the community it is there to serve have been met, and can be maintained. Understanding the HIA as a tool which is used as a 'means to the ends', or as a bureaucratic 'check-list' exercise negates the reason for using the tool to attend to health inequalities (Krieger et al., 2003).

These debates are further demonstrated in a letter to the editor "On the limitations of HIA" (Morgan, 2009), which spells out constraints in using the HIA including that 'HIA requires too many assumptions to reach a conclusion', and the perception that 'there are too many competing interests by those who are sponsoring or supporting an HIA to take place and those involved in an HIA' (PAGE NO?). HIA is based on causal relationships. This letter explains that the health of a population is decreased due to some change in health determinants which are controlled by policy, and decisions are made to address the health inequality by addressing the change in policy. It argues that in truth this is far too simplistic a way to view any health problem, and highlights the fact that assumptions about the reasons for health status as a factor of one change are made too often. In reality, health status is a factor of a holistic range of determinants (Lock, 2000; Krieger et al., 2003). Along with Quigley and Taylor (2003), Parry and Stevens (2001) believe that a full theoretical framework of an HIA is not often defined. This means that the full health effects of that policy change are also not likely to be understood. Joffe and Mindell (2002) and Locke (2003) talk about the neglect of an evidence base as one reason why the HIA is often undervalued.

The second reason cited in Morgan's (2008) letter to the editor is that too many competing stakeholder interests when doing an HIA can decrease its value. This can be a real limitation of the intersectoral nature of the HIA, which is the reason that the tool is touted to be so valuable, as it takes into account many different stakeholders' opinions to reach a decision and therefore the decision takes into account a problem from a holistic perspective. This intersectoral nature

also means that the interests of all the stakeholders involved in an HIA maybe different as well. The success of an HIA is not likely to be high if all stakeholders have a different interest in doing the HIA. There are many other reasons given as to the perception of the low value of HIA, including an unclear methodology (O'Connell & Hurley, 2009; Krieger et al., 2003), the need for an HIA to be systematic in its approach (Douglas, Conway, Gorman, Gavin & Hanlon, 2001), the difficulty of knowing when to perform an HIA to get maximum benefits – before or after the policy has been enacted, and the need to make efficient recommendations after the process of HIA has taken place (Douglas et al., 2001).

Though the HIA is a valuable tool, the perceived barriers must be addressed if it is to be institutionalised and reach its potential as a method to address inequalities experienced by people with disabilities that are a function of policy.

2.2.6.2 Barriers to HIA identified by New Zealand researchers

The New Zealand literature regarding the barriers reported in relation to HIA is similar to those in the international literature. However, several barriers facing HIA which are specific to the New Zealand context are discussed below.

Richard Morgan was President elect of the International Association for Impact Assessment at the time he wrote the article “Health Impact Assessment in Australia and New Zealand: An exploration of methodological concerns” (2001). He has written extensively about HIA in the New Zealand context. He talks of many barriers, including too much time being spent reinventing impact assessment in the form of HIA, as opposed to building on HIA. He explains that there are too many different models of HIA, and one can pick and choose what kind of outcomes one wants by choosing the model one uses. He talks about the way that HIA can be used at either a policy or a project level, and that there needs to be different methods to investigate each one, as it becomes problematic trying to use quantitative evidence to understand the health of a policy (Mahoney & Morgan, 2001).

The terminology used in impact assessment has been largely based on the biomedical model of health. This is not true of the HIA whose value is embedded in the social model approach that this tool takes in understanding health. Signal et al. (2006) also cite this definitional confusion as a reason that degrades the value of an HIA. They also cite that the time taken to get through the policy process was one reason why agencies they talked to in their paper “Strengthening Health Wellbeing and Equity” had little motivation to complete an HIA (Signal et al., 2006).

Morgan also talks of the need for political support if the HIA tool is to work to its potential (2008). This is also a reason that Langford gives in her NSW Public Health Bulletin (2006). Morgan also feels that clear lines of responsibility and accountability are necessary for the HIA to be effective, and also that it is necessary for all those involved in the HIA to have clarity of the aims of the HIA before it is undertaken. He feels sometimes this understanding is neglected by some stakeholders. He also states that a barrier to the HIA is when stakeholders hold different views of what constitutes health. A biomedical understanding of health can mar the productivity of the HIA, which takes into account a myriad of determinants impacting on health status (2008). Other reasons agencies preferred not to undertake HIAs that were stated in Signal,

Ward, Langford and Quigley's paper (2006) were a lack of resources which constituted time (as the process is perceived to delay the enactment of a policy), staff capacity, and confidence, and although agencies realised that their policies affected health of populations, they saw health as a responsibility of the health sector alone and did not feel that they had any part to play to protect health. Signal, Quigley and Langford (2006) also felt the central government too exclusive to welcome intersectoral work, which is integral to the working of the HIA tool.

The evaluation step of the HIA methodology has been cited as a further limitation. Lunt and McKegg (2003) and Quigley and Taylor (2003) write in their papers about the importance of evaluation as a means of justifying the growth of HIA. They state the importance of having clear aims and objectives in order to ascertain how well the HIA has achieved its goals, or the evaluation step. In Mahoney and Morgan's 2001 paper, a very pertinent New Zealand contextual issue of health protection in comparison to HIA is highlighted. The risk-based health protection model is a widely understood concept, and this poses a limitation to HIA whose method is not based on EIA which understands health in the risk assessment theoretical framework (Mahoney & Morgan, 2001). The value placed on HIA is questionable. It is perceived that health professionals view HIA as a stand-alone process or a means to an end. This negates any benefit of performing an HIA, as the tool is intended to highlight any limitations of policy and allow policy makers to change their policies to mitigate negative effects on the population (Mahoney & Morgan, 2001). Mahoney and Morgan (2001) highlight the need to bring attention to the mandatory requirement to investigate all groups affected by a proposal when undertaking an HIA. They say that the main stakeholders involved in the HIA can often dominate the process, and effects on other 'hidden' groups may not be assessed. Signal and Durham undertook some writing on HIA in the New Zealand policy context (2000). They talk of the need for political support for HIA, and the need for some sort of support for those performing an HIA; as there is little understood about the tool and how it is undertaken. The other cited obstacles which can limit the value of HIA include: a lack of evidence in defining the causal pathway of health inequalities; the technocratic interpretation of the HIA methodology, which often means that people performing the HIA can miss the main issues that the HIA can highlight; organisations often find it hard to rationalise the resourcing of an HIA; and the struggle to balance the cost/benefit of performing an HIA (Signal & Durham, 2000). Metcalfe and Higgins (2009) point out that often the link between policy decisions and HIA is not clear. This poses a de-motivating

factor for people who are thinking about undertaking the process to address health inequalities (Metcalf & Higgins, 2009)

Wise, Harris, Harris-Roxas and Harris (2009) write about the Australian experience of HIA. They identify that an HIA is most powerful when the stakeholders concerned with the HIA are involved in its conduct to ensure that there is a balance of both practical, experiential knowledge, in addition to theoretical knowledge when formulating outcomes to an HIA (Wise et al., 2009).

2.3 DISABILITY

People with disability are not always understood very well as a population. This section will review literature on the origins of disability, the contemporary models of disability and the limitations that are faced by people with disability.

2.3.1 *HISTORY OF DISABILITY IN THE WESTERN WORLD*

Around the time of the death of Christ (1AD), people with disability were accepted as an everyday part of society (Barnes et al., 1999). During this time, religious understanding was the most dominant influence in shaping people's views of disability. The Bible, which guided the religion of ancient Judaism, regarded many impairments as being sinful, unclean and unholy. This un-cleanliness was used as rationale to isolate disabled people from the mainstream society. However, the Bible also advocated against infanticide of babies born with impairments, and the provision of charity for those who could not feed themselves (Barnes et al., 1999).

With the emergence of Christianity, many of the same principles were advocated. Charity and alms-giving were important to the welfare of disabled people who had no family to provide for them (Barnes et al., 1999).

In the sixteenth century, however, due to plagues, poor harvests and immigration, there was an increase in the number of poor people needing welfare. In Britain, this need brought about the 'Poor Law'. This was the first state intervention in the welfare of its citizens. It involved people being taxed based on their own income and the subsequent redistribution of this money to those who were unable to provide for themselves (Barnes et al., 1999; Barton, 1996; Clapton & Fitzgerald, 1997).

Though these changes advocated a better recognition for disabled people, disability was still seen largely as a religious affliction. Witchcraft and Satan were often used to explain those who sustained a disability (Barnes et al., 1999; Davis, 1997; Clapton & Fitzgerald, 1997).

The eighteenth century brought a change from subsistence farming to industrialisation. This meant, among other things, that the nature of labour changed from one where the production of food involved a person, to one where the person operated a machine in order to produce food. This was not a conducive change for those with disabilities as it needed speed and dexterity; often complex tasks which were not suited to those with disabilities (Barnes et al., 1999; Davis, 1997).

During the nineteenth century, ideas changed and people with disabilities were stigmatised and labelled as a 'social problem' and hidden away in asylums. Housing these people in asylums was seen as an economically beneficial way to provide for them (Barnes et al., 1999; Davis, 1997).

A change in dominant thought that 'medical misadventures' could explain wellbeing of an individual brought a change to the requirement of disabled people to prove their disability. The knowledge that medical conditions were the reason for their 'disabled status' rationalised people with disabilities being kept isolated, categorised and subject to different conditions based on their impairment (Barnes et al., 1999, Davis, 1997).

In response to this disadvantaged population, new medical professionals and specialists created a field of work called rehabilitation therapy. In this field, the allied health professionals worked to 'cure' or 'rehabilitate' the impairment or the reason for the disability. This proved contentious as many disabilities were not able to be 'fixed'. People with disabilities lost any independence and were instead 'helped' by professionals to fit into the norm, and ensure they were not a burden on society (Bryan, 2000; Barnes et al., 1999). This model was known as the 'individual' or 'medical' model, and placed the responsibility of the disability squarely in the hands of its recipient (Barnes & Mercer, 2006; Barnes et al., 1999; Campbell & Oliver, 1996; Oliver & Barnes, 1998).

This history has left this population with similar psychological ramifications as many other marginalised groups. The understanding that people with disability have of themselves is one where they perceive themselves to be second-rate citizens, and a burden on society (Reeve, 2002). They may not have confidence to express how they feel, as society has taught them that

they should be grateful for any aid they receive, and they are expected to contend with the barriers that are a function of mainstream policy in their everyday lives.

However, during the 1900's there was a major shift towards deinstitutionalisation which sought to 'normalise' people with disability and to mainstream them wherever possible. This has brought people with disabilities into the wider society much more. However, it was and still is questionable to what extent the community has been ready to accept people with disability as many structures and services still fail to take into account their needs (Barnes et al., 1999).

2.3.2 CONTESTED UNDERSTANDINGS OF DISABILITY

Disability has many definitions depending on the context it is used in and who is using it (Barton, 1996). Historically, as discussed in the previous sub-section, disability has been understood in terms of the 'medical model'. This 'individual' model of disability continues to dominate many people's understanding of disability and attitudes towards the disabled. This model advocates for the diagnosis and solution of disability to lie firmly in medical knowledge on the assumption that disability is part of the individual (Barnes et al., 1999; Thomas, 2009; Shakespeare, 2006; Oliver & Barnes, 1998). This model understands that once someone has been diagnosed as 'disabled', the disability then becomes their defining characteristic and their limitation rationalises their need for 'care and attention as a helpless victim'. The most preferred treatment for disability is intervention and rehabilitation from allied health professionals, psychologists and medical doctors until the person with a disability becomes 'normalised' as anticipated in medical intervention (Thomas, 2009; Barnes et al., 1999; Darling, 2003; Oliver, 1998; Barnes & Mercer, 2003; Campbell & Oliver, 1996; Oliver & Barnes, 1998).

A more contemporary socially informed perspective on disability has developed recently (Oliver, 1998), and is referred to as the 'social model of disability'. This model places the person with the impairment at the centre of the model, as opposed to the problem or disability. Michael Oliver, one of the first to begin discussions on the different models of disability, defines in his book *Disability: from theory to practice* (1998) the differences between the medical and social model of disability. While the medical model sees a disability as a result of personal tragedy, the social model sees the disability as a result of social oppression. The medical model sees disability as a personal problem while the social model puts the responsibility of the disability down to society. The medical model sees medical intervention as the only way to 'normalise' the person with the

impairment to be a part of society, while the social model advocates for social change of institutional barriers. The medical model endorses that people with disabilities should be controlled as they are 'deviant' and not able to live independent lives, whereas the social model advocates that behaviours that people with disabilities exhibit should be shown tolerance and, that as opposed to 'care' which denotes that someone else makes their decisions, should have 'rights', and be able to make their own decisions and choose their own destinies (Oliver, 1998; Barnes & Mercer, 2003; Barnes et al., 1999; Campbell & Oliver, 1996; Oliver & Barnes, 1998; Thomas, 2009; Darling, 2008; Adkins, 2003). Although these models can be used in conjunction, people with disability are often viewed exclusively in terms of one model.

This social construction of disability understanding underpins the New Zealand Disability Strategy (ODI, 2001). The Strategy takes the social model understanding and makes the point that disability is different from impairment (ODI, 2001). It argues that impairment is a biological construction, whereas disability is a social construction. It goes on to explain the way that society makes impairment into a disability via their negative attitudes towards people with impairments, and the ways in which these impairments are ignored when policy is being made, which in effect, disables individuals with impairments (ODI, 2001). This is the understanding taken of people with disabilities in the HIA guidelines (PHAC, 2005).

This social model of disability is analogous to the social model of health defined in the HIA procedures (PHAC, 2005). This broad understanding found in both models acknowledges that 'health' in both cases is influenced by wider-societal attitudes and imperatives. This makes the HIA a valuable tool to understand the constraints that policy places on people with impairments. For the purposes of this research, I will use the definition that has been used in the Disability Strategy (2001). I have chosen this social definition of disability as it underpins the topic of my research, which understands health as a social construction. Policy has been created by society, and society is what disables people.

2.3.3 THE LEGISLATION UNDERPINNING DISABILITY RIGHTS IN NEW ZEALAND

Securing disability rights in New Zealand has been a long-standing political struggle and one which has only been formally acknowledged by the Parliament within the last 20 years. This struggle to recognise disability rights in New Zealand has been part of a worldwide movement.

As the Second World War began to close, the world climate was ready for a great leap forward in the recognition and observance of human rights. Minority Groups began to gain power, and this particularly focused on civil rights in the United States of America. The Civil Rights Movement made it illegal to discriminate against anyone based on sex, race or national origin. However, disadvantaging an individual based on physical or intellectual impairment was not included. The issue is still being contested, and lobbying from Disability Rights Groups has endorsed its status as a legislative issue (Bryan, 2000; Bailey, undated; Beatson, 2001). Disability, like ethnicity, is a condition that is not a choice of the recipient. It is therefore a condition covered under recent Human rights legislation, which advocates identical rights of disabled and non-disabled in all sectors of life (Human Rights Commission, 1998).

Following international trends, New Zealand enacted its own Human Rights Act in 1993 that was largely created to address the bi-cultural inequalities in New Zealand. However, this was further amended in 1994 to include disability rights. This defined discrimination as when ‘someone with a disability is treated less favourably than someone without a disability’ (Human Rights Commission, 1998). The document also defines indirect discrimination as ‘where a condition is imposed which, although the same for everyone, unfairly disadvantages people with a disability’ (Human Rights Commission, 1998). The Human Rights Act covers discrimination against people with disabilities in employment, business partnerships, vocational training and qualification authorities, access to public places, provision of public services, educational establishments and provision of goods and services (Human Rights Commission, 1998). This is the most important piece of consequential legislation that governs people with disability in New Zealand today; however, there are many situations where this legislation is side-stepped in catering for people with disabilities.

The Labour Alliance government that came into office in 1999 took a much stronger stance on responding to the needs of people with disabilities. In 2000, a major health sector restructuring devolved the responsibilities of the Ministry of Health (MOH), which included disability support services, to 21 District Health Boards around the country (The New Zealand Parliament, 2009). This also brought the enactment of a new ‘Health and Disability’ Act (The New Zealand Parliament, 2009). One of the objectives of this act was to release a new document that took into account the social model of disability, and a commitment to human rights (Clarke, 2001). It aimed to further eliminate barriers for people with disabilities ‘wherever they may exist’ (Office

for Disability Issues, 2001). This resulted in The National Disability Strategy, which spells out fifteen objectives designed to make life for disabled people more equitable to mainstream society based on the values of respect and equality (Clarke, 2001).

2.3.4 NATIONAL DISABILITY STRATEGY (2001)²

This document provides a social model understanding of barriers that people with disabilities face in a New Zealand context. The aim of the New Zealand Disability Strategy ‘Making a world of difference – Whakanui Oranga’, is to eliminate these barriers wherever they may exist (Office for Disability Issues, 2001). The strategy aims to work by using a two-tiered method:

Firstly, it begins with a focus on changing the ways that disability is addressed in government (Clarke, 2001; ODI, 2001). The strategy provides a framework to ensure that consideration is given to people with disabilities in any decision-making process. Government departments are also required to give an evaluation as to what extent they have taken the strategy into account in their proceedings at the end of every year (ODI, 2001). In this way, government is taking the lead in changing the ways that people in New Zealand address the needs of those with disabilities.

The second part of the two-tiered process is a change in attitudes by wider society (ODI, 2001). The strategy also provides a framework for society to take consideration and increase their understanding of the needs and issues that people with disabilities and their families face (Clarke, 2001). The hope is that as the government recognises people with disability by designing disability friendly policy, the rest of society will too (ODI, 2001).

This strategy has been further backed up by the United Nations *Convention on the Rights of Persons with Disabilities* (2007).³ This document, similar to the New Zealand Disability Strategy, promotes the rights of people with disabilities at every stage of life. It is a legal framework that holds governments accountable when they do not abide by the 50 articles covering all parts of the lives of people with disabilities. New Zealand was a leader in the negotiation stage of this treaty and endorsed the principles of inclusion by sending people with disabilities to lead them. New Zealand signed this convention on the 30 March 2007, and further ratified it on the 26 September 2008 (ODI, n/d).

²This document can be found in Appendix A.

³This can be found in Appendix B.

2.3.5 BARRIERS FACED BY PEOPLE WITH DISABILITIES

The barriers that people with disabilities face are wide-ranging and all are partly due to the adverse effects of policy. Attitudes that some able-bodied people have towards people with disabilities have been the subject of the majority of complaints received by the Human Rights Commission (ODI, 2001). Negative attitudes can be proliferated by stigma, prejudice and discrimination. The *Disability Strategy* (2001) guides government departments to take more cognisance of those with disabilities within their proceedings. The strategy runs on the principle that when government starts to consider and cater for people with disabilities, society will too (ODI, 2001). A summary of the major barriers faced by people with disabilities that are defined in the strategy are defined below:

2.3.5.1 Income

For parents with children who have disabilities, the economic demand posed on families often means that children do not get a head start in life (ODI, 2001; Beatson, 1996). Adults who have disabilities find it hard to gain employment. Even if they have gained a tertiary degree, they will earn on average less than their able-bodied counterparts who did not gain a tertiary degree (ODI, 2001; Ministry of Health, 2004; Beatson, 1996; Goggin & Newell, 2005).

2.3.5.2 Education

Disabled teenagers are a lot less likely to leave school with a qualification than their non-disabled counterparts (Ministry of Health, 2004; ODI, 2001; Goggin & Newell, 2005). Communication barriers have meant that people with disability experience literacy problems (ODI, 2001; Goggin & Newell, 2005).

2.3.5.3 Lack of Social Support Networks

Adults also find it hard to find somewhere to live, due to poverty, or due to peoples' dislike of having supported housing in their area (ODI, 2001; Goggin & Newell, 2005). As a group, people with disabilities have lower incomes and fewer family and financial resources. The financial cost of disability is high, and often families with disabled children have an impaired earning potential as they need to provide support for their children (ODI, 2001; Goggin & Newell, 2005). Ignorance and fear are the reasons that able bodied people shut many people with psychiatric

and intellectual disabilities out of social and community networks, making their participation in society less than desirable (ODI, 2001; Barnes et al., 1999).

2.3.5.4 Physical Environment

Accessibility can pose a significant barrier for people with disabilities as many public and private buildings, and even marae, are not accessible to those whose medium of mobility is not walking (ODI, 2001; Goggin & Newell, 2005).

2.3.5.5 Gender

Being a woman with a disability is a double disadvantage. On average, women earn less than men, and on average disabled women earn less than able-bodied women. Disabled women earn an average income of \$15,000 per year (ODI, 2001; Ministry of Health, 2004). People who are of an ethnic minority and also have a disability are further disadvantaged (Goggin & Newell, 2005; ODI, 2001).

2.3.5.6 Access to Health Services

The lower the socio-economic area someone lives in, the less disability support services are provided (Ministry of Health, 2004; ODI, 2001). Both Māori and Pacific peoples tend not to use disability services, even though 44 percent of Māori with long term impairments report that they need services (Ministry of Health, 2004).

2.4 LINKING DISABILITY AND HIA

HIA and disability has not been a widely explored area. This section provides a review of the existing literature.

2.4.1 THE DETERMINANTS OF HEALTH

Many of the barriers that people with disability face can also be defined as ‘determinants of health’. The determinants of health have been defined within the discipline of Public Health. If a population shows a low status in each of the defined criteria that follow, they are known as a ‘disadvantaged population’:

- Income and social status – higher income and social status are linked to better health.
 - Education – low education levels are linked with poor health, more stress and lower self-confidence.
 - Physical environment – safe water and clean air, healthy workplaces, safe houses, communities and roads all contribute to good health.
 - Employment and working conditions – people in employment are healthier, particularly those who have more control over their working conditions.
 - Social support networks – greater support from families, friends and communities is linked to better health.
 - Culture – customs and traditions, and the beliefs of the family and community all affect health.
 - Genetics – inheritance plays a part in determining lifespan, healthiness and the likelihood of developing certain illnesses.
 - Personal behaviour and coping skills – balanced eating, keeping active, smoking, drinking, and how we deal with life's stresses and challenges all affect health.
 - Health services – access and use of services that prevent and treat disease influences health.
 - Gender – men and women suffer from different types of diseases at different ages.
- (WHO, n/d, *Determinants of Health*)

Arguably, the above determinants of health are analogous to the defined barriers that people with disabilities face as presented in the last section. It can then be argued that people with disabilities are more likely to meet the above criteria of determinants of health to be classed as a 'disadvantaged population'. This is also how people with disability are classified in the HIA procedures. However, people with disabilities also face the added barrier of negative public perceptions or attitudinal barriers, as defined in the social model of disability.

During the course of scoping the relevant literature for this study, I found literature on HIA and disability only present in the form of reports of performed HIAs.

2.5 CONCLUDING COMMENTS

Based on the above literature review, the key points in my argument so far are as follows:

- International and New Zealand HIA literature gives minimal consideration to the link between HIA and people with disability. This is a policy and research gap that needs to be addressed.
- The understanding of causes of disability, barriers and appropriate policy responses is contested in the international literature. Hitherto, this understanding has been dominated by the medical model of disability. More recently, the social model is seen to provide a broader, contextually informed understanding of disability compared to an individual, problem-centred perspective.
- New Zealand's HIA procedures reflect the underpinnings of the social model of disability. Arguably, New Zealand HIA procedures are socially sensitive to acknowledging the social and institutional barriers that people with disability face. Hence, one could hypothesize that HIA practices in New Zealand would reflect this inclusivity of the social model of disability. This thesis will seek to provide a deeper understanding of this assumption.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

As someone who experiences daily the social barriers of living with a disability, I understand well that the general public are sometimes not aware of the barriers that people with disability have to contend with in their everyday lives. As a person with a disability, I assumed that within the work of the practitioners who use a tool that focuses on the assessment of ‘equity’ in policy, a strong consideration and acknowledgement of people with disability would be present in performed HIA cases. However, this expectation has not been entirely borne out in practice in relation to Health Impact Assessment in Aotearoa/New Zealand. This research sets out to unravel the factors influencing disability awareness in HIA policy in New Zealand.

In this chapter I discuss the research methodology that addresses this problem as defined in the research questions stated in chapter one.

CHAPTER OVERVIEW:

- Section 3.2 presents the rationale for the theoretical framework chosen to guide this research.
- Section 3.3 discusses the process and rationale of the mixed methods research strategy used in this study.
- Section 3.4 provides an overview of the broader context of the time during which this study was undertaken.
- Section 3.5 will give an overview of the sequential steps of the research process in order to address the objectives this study, as detailed below.
 - Section 3.5:1 reports on the process the preliminary literature review to provide a conceptual context to the research.
 - Section 3.5.2 discusses the method of situating New Zealand’s HIA policy guidelines into the international context.
 - Section 3.5.3 discusses the method of situating New Zealand HIA practice in an international context.
 - Section 3.5.5 outlines the interview process and methods of analysis, as follows:

Section 3.5.5.1 discusses process for making contacts for the interviews.

Section 3.5.5.2 outlines the process I took to conduct the interviews. Finally, Sections 3.5.5.3 (a) and (b) summarise the methods I used to analyse the data collected from the interviews. This involved, firstly a thematic analysis of the conversations I undertook with my interviewees that constituted the reasons for the exhibited disability awareness in HIA practice, and then the process of constructing a potential meta-analysis, which allows me to draw conclusions to this research.

- Section 3.6 provides a critique of the mixed methods approach used in this research.
- Section 3.7 discusses the ethical issues and how they were dealt with.
- Section 3.8 provides my personal reflections on the experience of undertaking this study as a personal journey.

3.2 GUIDING THEORETICAL FRAMEWORK

Creswell, in his book *Research Design* (2000), highlights the importance of defining research questions when undertaking any research study (Creswell, 2000, p.105). The questions that I chose to guide my research were:

- i) What is the relationship between the HIA policy guidelines and the recognition of disability issues in HIA reports in New Zealand? And;
- ii) What are the factors that contribute to this relationship?

As I read the literature concerning the relationship between disability policy and practice, I gained insight into a number of ways this relationship could be explained in the HIA context. Expressing habitual conditioned responses when catering for people with disabilities can define these relationships, but these are often underpinned by more deep-seated factors, which despite not being specifically identified by the practitioners, may be present in their practice. These reasons are best understood when analysed in the grounding of the ‘social model of disability’, as this model takes into account both structural and attitudinal factors when explaining ‘disability’

(Barnes, Mercer and Shakespeare, 1999). The social model of disability is the theoretical model that will underpin the analytical framework for this study (Creswell, 2009; Neuman, 1994).

3.3 MIXED METHODS METHODOLOGICAL STRATEGY

In order to answer the research questions, I undertook a policy analysis of the HIA policy and practice as it relates to people with disabilities. This analysis used both quantitative and qualitative methods to investigate this research problem. Neuman, in his book *Social Research Methods* (1994) states that ‘social researchers systematically collect and analyse empirical evidence in order to understand and explain social life. But a qualitative researcher goes about it differently than a quantitative researcher does’ (Neuman, p.316).

Quantitative methods are programmatic, beginning with a theory to a hypothesis (Creswell, 2009, p. 3; Neuman, 1994; Somekh & Lewin, 2005; Payne & Payne, 2004; Morse & Niehaus, 2009). This is also known as a deductive process (Neuman, 1994; Bryman, 2004) where theory guides research (Somekh and Lewin, 2005; Bryman, 2004). A quantitative researcher often takes a positivist approach and only acknowledges what can be seen and measured to relate to understanding a relationship (Payne & Payne, 2004; Bryman, 2004). Researchers will then formulate a research question (Neuman, 1994) and defines concepts and variables to measure and enable them to test their hypothesis (Payne & Payne, 2004; Somekh & Lewin, 2005; Neuman, 1994).

Data collection starts with taking a concept, construct or idea (Morse & Niehaus, 2009; Neuman, 1994) and then devising instruments to empirically measure social interactions, behaviours or attitudes and transform them into data (Somekh & Lewin, 2005; Creswell, 2009; Neuman, 1994). The procedures are both standardised and reproducible (Neuman, 1994; Payne & Payne, 2004). The data that is extrapolated is in the form of numbers borne out of precise measurement (Neuman, 1994; Payne & Payne, 2004).

Analysis is undergone by means of statistics, with the interpreting and presenting of the statistics to either prove or disprove the hypothesis (Creswell, 2009; Somekh & Lewin, 2005; Payne & Payne, 2004). These statistics can be presented in tables or graphs, and what they present will

either prove or disprove the hypothesis (Neuman, 1994; Somekh & Lewin, 2005). These define the conclusions to the study, and may cause the researcher to have to change their ideas and reformulate their hypothesis.

Qualitative inquiry generally deploys different knowledge claims which are known as inductive (Creswell, 2009; Neuman, 1994; Yin, 2011). Knowledge is created when the research generates the theory (Bryman, 2004, p. 20; Yin, 2011; Stake, 2010). This means that, as opposed to quantitative research, theory is much more varied (Creswell, 2009). A qualitative researcher understands that theory is a product of many inter-related concepts. This is understood as an interpretivist approach (Bryman, 2004; Neuman, 1994; Yin, 2011; Stake, 2010). This research stresses the socially constructed nature of reality (Denzin & Lincoln, 1998). A precondition that enriches the research is an intimate relationship between the researcher and the subject matter (Denzin & Lincoln, 1998; Creswell, 2009; Stake, 2010). The research questions generated in a qualitative study are usually measured in “an ad-hoc manner and are often specific to the researcher or situation” (Neuman, 1994, p.317).

The methods of investigation and data collection used in a qualitative study differ from those in a quantitative study (Creswell, 2009). Data are gained in the form of words from mediums of conversations, or observations (Neuman, 1994; Stake, 2010; King & Horrocks, 2010; Silverman, 2010) and is evaluated in an analysis consisting of themes, motifs, generalisations or taxonomies (Neuman, 1994; Yin, 2011; Bernard & Ryan, 2010).

Conclusions are reached when the findings of the research paint a consistent and coherent picture (Neuman, 1994; Stake, 2010). Though the conclusions are important, the effort of a qualitative research project consists mostly in the qualities, processes and meanings that are examined (Denzin & Lincoln, 1998). The answers to the initial research aims foremost to seek to stress how ‘social experience is created and given meaning’ (Denzin & Lincoln, 1998, p. 8; Yin, 2011; Stake, 2010).

There are some who debate the combined use of both the quantitative and qualitative method to address one research problem (Brennan, 1992; Bullock, Little & Milham, 1992). Some academic researchers feel that the two approaches are fundamentally different, and therefore are not able to complement each other in the investigation of a research study (Brannen, 1992, p. 81; Morse & Niehaus, 2009). I would argue, following Ann Oakley, that using mixed methods can provide a richer understanding of the questions being addressed (Oakley, 1998; Creswell, 2009; Bryman,

2004; Morse & Niehaus, 2009). Adopting this approach in my study has enabled me to use the appropriate tools for the two parts of this project. This study uses cross-national, top-down quantitative approaches to policy analysis to understand the relationship between HIA policy and practice in relation to disability. This then allows me to use bottom-up qualitative interviews with expert HIA practitioners and policy-makers to explore possible reasons for the relationships elucidated quantitatively. Using mixed methods is thus suited to the research presented here. Understanding the relationship between policy and practice through documented quantitative data gives a verifiable and reproducible statement about the nature of the relationship. It provides a solid grounding for discussion of the reasons for a discrepancy discovered between policy and practice (Denzin & Lincoln, 1998) of HIA in New Zealand.

The investigation of this relationship involved the utilisation of qualitative methodologies in the form of analysed in-depth qualitative interviews with HIA policy makers: Interviewee B, Interviewee C, and Interviewee D, and HIA practitioners Interviewee A, Interviewee C, and Interviewee E. These expert interviews provide in-depth perspectives on the attitudinal, structural and contextual factors influencing the practice of HIA, and can provide insights which are not available through documentary sources.

3.4 TIMING OF THE STUDY

The fieldwork for this research was undertaken in the months of May-September 2010. This was a time when the new National Government had taken what I consider to be punitive actions such as downsizing Public Health units and cutting funding of programmes to cater for minority populations (The New Zealand Parliament, 2009). Although the theoretical support for HIA in the academic world was still high, its practical application in New Zealand was becoming questionable (Pers com, Margaret Earle, April 28, 2011). Nevertheless, many of the HIA reports analysed in the quantitative study date from the era of the Labour government, when HIA was still fairly new, and though the institutionalisation of this tool was not well established, government support for the HIA was still relatively high within pockets of central government, regional government, and academia (Pers com, Margaret Earle, 28 April, 2011). At the time of the research, disability issues also had a rejuvenated clout for a short time, with the Minister of Disabilities, Tariana Turia, securing a large fiscal budget from the government (The New Zealand Treasury, 2009). Thus, in terms of interest in and support for disabilities equity during the period of this research, the contextual setting can be described as ‘mixed’.

3.5 THE RESEARCH PROCESS

The methods I used to answer the two defined research questions above are described in this section.

3.5.1 LITERATURE REVIEW

A literature review was initially undertaken to provide the background context to the research that follows. This literature review continued throughout the course of my research as new conceptual insights were needed to interpret the research findings. This can be seen in chapter two.

3.5.2 SITUATING NEW ZEALAND HIA POLICY GUIDELINES IN THE INTERNATIONAL CONTEXT

The quantitative phase of the fieldwork began with the first research question: How is New Zealand placed in their consideration of people with disabilities in HIA practice within a global context?

To answer this, I undertook a policy content analysis which analysed the HIA policies of four countries (Yang & Miller, 2008, Chapter 35). The countries chosen are comparable to New Zealand in several respects. They are all English speaking, are all developed countries, and all draw from an English legal framework. The four countries chosen also share a common academic literature around issues of disability and historical shifts in the terrain of political ideologies. At the same time, they are variable in their degree of commitment to disability issues, the size of their populations and in geographical location. I analysed the HIA policy guidelines of England, Scotland, Australia and New Zealand, using the following sources:

- *The Merseyside Guidelines for Health Impact Assessment*. Scott-Samuel, A., Birley, M., Ardern, K., (2001).
- *Health Impact Assessment Guidelines*, Commonwealth of Australia, 2001.
- *A Guide to Health Impact Assessment: A Policy Tool for New Zealand*, Public Health Advisory Committee Te Ropu Tohutohu i te Hauora Tūmatanui, 2005.
- *How to do Health Impact Assessment: a guide for practitioners*. Margaret Douglas, Scottish HIA Network (March 2009).

I undertook this analysis in order to interpret the HIA report literature in relation to its wider global context. The policy content analysis investigated the number of times each set of HIA guidelines that each respective country deployed cited people with disabilities as an important population to be considered in the HIA assessment. As these guidelines are not written to focus on any particular disadvantaged population, but rather to guide the reader in how to carry out an HIA, I felt that acknowledgement that people with disability were part of the list of disadvantaged populations who were pertinent to the HIA was adequate to remind HIA practitioners that this was a population that was worthy of their consideration.

In each set of guidelines, all the mentions of ‘disability’ were located. Then the context of each of these mentions was analysed. These mentions were only acknowledged as important to the research if they were in the context of ‘an important group to assess in HIA.’ In the New Zealand guidelines, there were eleven mentions of disability. The New Zealand HIA guidelines acknowledged people with disability eleven times, which reflected the principle of inclusion, integral to the social model of disability. The other notable feature of the New Zealand HIA guidelines was the social-model of disability understanding that is referred to in the underpinning of the document through reference to the *New Zealand Disability Strategy* (ODI, 2001). This was considered important as it was unique to the New Zealand guidelines and the most current international model of the understanding of people with disabilities.

Finding one representative set of guidelines for each country involved in the research proved difficult in some cases, as there were numerous HIA guideline documents written for the different countries, with each set of guidelines taking a different focus. I located contacts of people involved in the HIA process within each of the four countries who were able to define which guidelines were the most commonly used guidelines. However, I still cannot be sure that the guidelines I have assessed in this research are the guidelines that were used when undertaking the assessment of the HIA case reports that I have analysed. These are further defined in the next part of this research.

3.5.3 SITUATING NEW ZEALAND HIA POLICY PRACTICES IN THE INTERNATIONAL CONTEXT

Having established the level to which the HIA guidelines of each country involved in the investigation considered people with disabilities in their procedures, I now sought to understand if this guiding rhetoric was mirrored in their HIA practice. I did this by undertaking a quantitative case study analysis of performed HIAs (Silverman, 2010). HIA case studies were

obtained from all the countries whose HIA guidelines had been analysed. These case studies were analysed in a quantitative fashion based on to what level they considered disability in the HIA case that had been performed.

Inclusion and exclusion criteria were strictly adhered to in order to make a valid comparison between the case studies that were analysed. This meant they needed to start from an equal level in terms of their aims, and the issues they covered and have the potential to reach the same level of outcomes. Those which differed in these defined factors were excluded from the quantitative analysis (Bleijenbergh, 2009).

Case studies were excluded under the following criteria:

- Mental wellbeing assessments were not included
- Equity focused assessments were not included
- Scoping reports were not included
- Any HIAs on specific disability issues were not included
- Any HIAs on specific issues which would affect the population homogeneously (including people with disability) were not included
- Any HIA which did not contain the opportunity to reach a level 5 classification were not included.

Case studies were included under the following criteria:

- Any report on an HIA which included all parts of the process (theory, screening, scoping), and had to give recommendations, i.e. had to be a full HIA, not a screening or scoping report.
- Those which fitted in with the criteria defined above were measured against a scale (0–5).
- This scale was developed to provide a framework analogous to the stages in the HIA process.
- This scale aimed to parallel the five most indicative stages that could be reached in the assessment of an issue in the HIA process, and understand to what level the awareness of disability was considered in each particular HIA.

The classifications are as follows:

CASE STUDY DISABILITY INCLUSION CATEGORIES

- 0- Contains no disability inclusion within the case study.
- 1- Contains inclusion of disability only in HIA theory.
- 2- Contains inclusion of disability only in theory and screening stage of HIA.
- 3- Contains inclusion of disability only in theory, screening and scoping stage of HIA.
- 4- Contains inclusion of disability to a level 3 and also translates scoping into recommendations to cater for disability in a non-specific way.
- 5- Contains inclusion of disability to a level 4 and also translates scoping into recommendations specific to disability.

Within all the HIA reports analysed from each country, the scores for each category were then totalled and expressed as a percentage of the total scores obtained for that country. This percentage was indicative to the level of disability awareness each country demonstrated in their HIA practice. As the sample sizes of the assessed cases were different for each country, expressing the results of the analysis as a percentage allowed for comparable comprehension as to what extent each country took consideration of disability awareness in the HIA process.

The construction of the categories was very much accomplished by a trial and error method. Only after about four weeks of using my initial classifications did I come to a conclusion of what the final categories would be. This was because throughout the four weeks of analysis, I was presented with case reports which provided me with new issues which I had not encountered and therefore the categories I was using did not cater for. In the end, the five stages that I settled on were deemed the most appropriate and valuable way to understand to what level disability inclusion was practiced in each country.

Finding enough case studies to constitute a data set that was substantial enough to be indicative of any conclusions proved difficult in the case of New Zealand, Scotland and Australia. Of great help was the Online HIA community I accessed through Jessica McCormick, an academic at Monash University in Australia. She advised me to join the global HIA forum the 'Asia Pacific HIA List Server'. I was then able to ask many people for resources from different countries. Initially, I analysed case studies from all United Kingdom (UK) countries, the European Union (EU) region, North America, Australia and New Zealand. However, due to the varied methods

of political administration deployed by each country/region, and therefore the different interpretations of both people with disabilities, and the HIA policy in these countries/regions, any conclusions I drew about some countries/regions were not interpretable in a global comparable context. I also faced the problem of my inability to obtain enough case reports to constitute a sound data set for each country/region which meant the data had a large margin of error, and may not have been indicative to any conclusions. This meant I had to narrow my scope of countries. I finally decided on using data from England, Scotland, Australia and New Zealand as they had comparable socio-economic contexts and enough case studies to draw substantial conclusions about the level of disability awareness in HIA practice in each country.

The results of this quantitative analysis presented the UK countries (Scotland and England) with the highest disability awareness, followed by Australia and then New Zealand. New Zealand showed an apparent 'gap' in the disability awareness between the HIA policy and HIA practice. The next part of my research sought to better understand the reasons for this inconsistency.

3.5.4 UNDERSTANDING THE GAP BETWEEN POLICY AND PRACTICE FROM A THEORETICAL PERSPECTIVE FOLLOWED BY VERIFICATION USING IN-DEPTH INTERVIEWS

Further literature review

A literature review was undertaken to find theoretical explanations for the observed relationship between policy and practice of disability issues in HIA in New Zealand. This review found three bodies of literature to explain the observed relationship.

The first was the 'Unconscious attitudinal barriers faced by people with disabilities'. This literature was specific to people with disabilities and could also explain the observed relationship between policy and practice when assessing disability issues in the HIA in New Zealand. This body of literature concerned any attitudes that people possessed about those with disabilities. This included examples of articles explaining the way that differential understandings the 'social model' of disability between different stakeholders can render the implementation of a disability policy ineffective (see section 6.3.1).

The second body of literature found was that of 'Generic HIA barriers', which were not specific to disability, but could explain the reasons that there is unfulfilled potential when assessing

disability issues in HIA practice in New Zealand. The main explanations that could potentially apply to this research are a lack of funding and resources. A less-specific generic barrier which could also potentially provide explanation is the political ideology of the government in office at the time of the assessment, and hence the differential priorities (see section 6.3.2).

The third and final body of literature found in this review to explain the observed relationship between policy and practice when assessing disability issues in the HIA in New Zealand was based on the 'Feminist interpretations of the construction of Disability.' These explanations focused on the way that people with disability are socially constructed as 'other', which rationalises their unequal treatment in society. I have adapted feminist discussions of the 'othering' of women, using five mechanisms identified by Val Plumwood (1993) through which 'othering' occurs (see section 6.3.3).

In-depth interviews

Armed with theoretical explanations as to why I had observed the relationship between the HIA policy guidelines and the practice concerning disability awareness in HIA in New Zealand, I now needed a method to verify one of the schools of thought that my literature review had uncovered. The most rigorous way that I could do this was to conduct a bottom-up approach to policy analysis using semi-structured interviews (Warren & Karner, 2010, pp.129-130) with six experts involved in the HIA field. These people would have the best ability to verify and confirm any of the three bodies of literature reviewed, or to give any new explanations for the observed relationship between the rhetoric concerning disability in the HIA policy guidelines and the practice of disability awareness in HIA in New Zealand.

Semi-structured interviews were undergone with both HIA practitioners and HIA policy makers. I felt this method of interview was the most valuable way to achieve my goal of the qualitative analysis, as it allowed each interviewee to answer my questions, while still emphasising what they perceived as important information to communicate. In this way, I did not dictate what information was communicated to me as I had limited control over what direction the interview took (Creswell, 2009, p.188; Denzin & Lincoln, 1998). I completed six interviews in total; two with HIA practitioners, four with HIA policy makers and one extended interview with a HIA policy maker/practitioner where questions were answered wearing the hat of an HIA policy maker, and subsequently that of an HIA practitioner. This was done to try and get as many

perspectives and explanations of the issues observed of the gap between the guidelines and practice of disability awareness in HIA. In hindsight, the HIA practitioners shed more light on the reasons for the lack of awareness of disability in the HIA process than the policy makers. It may have been more beneficial to interview other HIA practitioners, as opposed to policy makers.

3.5.5 INTERVIEW PROCESS

3.5.5.1 Making contacts for interviews

Making the contacts for the interviews was a fairly straightforward process. This was largely due to the fact that the people I needed to talk to were located in the Public Health Sector, and as I had completed my Postgraduate diploma in Public Health, I already had plenty of contacts. I wrote an email to Pauline Barnett who is a Doctor in the discipline of Public Health, asking if she had any contacts who would be able to help. She replied by giving me the contact of Margaret Earle who worked for the HIA Support Unit in Wellington, and has also been part of the PHAC. I contacted Margaret and requested her help to find some contacts. She responded by emailing me contacts of people who were on the PHAC at the time the policy guidelines were written. She also rang me and gave me the names of some HIA practitioners who would be valuable to interview.

Busse (2003) defines that making contacts should be achieved via “a letter – purposefully addressing the potential interview partner – the expert shall at first be informed about the goals and the subject of the project. This letter should also announce a first telephone call. This call should be some days later and inform the expert about what to expect in respect of time expenditure and content, to then talking about his readiness for an interview. By a third step, the actual telephone interview is conducted” (Bogner, Littig & Menz, 2009, p. 164).

I then emailed the following: a key informant referred by Margaret who was the Director of the PHAC at the time the HIA guidelines were written, but had been out of the field for five years; a key informant who was the team leader of the PHAC at the time the HIA guidelines were written; a key informant who worked in the PHAC when the HIA guidelines were written and is presently an HIA practitioner; a key informant who is an HIA practitioner who has been working in the field for less than ten years; a key informant who was a Secretariat to PHAC at the time the HIA Guidelines were written but has been out of the field for five years; and a

prominent HIA practitioner who has worked in the field for longer than ten years, to ask for an interview via phone. All responded and were happy to undergo the interview process. When we had arranged a time for the interview, I emailed them a set of questions which I would base my interview on. These questions differed depending on their representative position.⁴ Interviews were conducted by phone and lasted between one and one-and-a-half hours. They were recorded by a Dictaphone before being transcribed (Schostak, 2006, p. 125).

One of the informants who lives in my locality was able to meet me in person. We did this on two occasions (as we had technical difficulties on the first occasion). He gave me two hours on the second occasion, as I interviewed him as both an HIA policy maker and an HIA practitioner.

At a later date, I also emailed two other informants to ask for an interview. One had been highlighted as a valuable contact who was an HIA practitioner and has been working in the field for over ten years. I also requested an interview from an academic in the discipline of Public Health who works in the HIA Research Unit at The University of Otago. The latter of these responded declining the invitation as she was too busy, however, the former agreed.

3.5.5.2 Conducting the interviews

Interviews were all conducted on the phone (Neuman, 2006, pp.244-245) except Interviewee C's which was conducted at my office at the University. I feel that my interview with this informant, as it was face-to-face (Schostak, 2006, p.125) was much more valuable than my other interviews on the phone. I felt that as I was able to talk face-to-face with Interviewee C, it was more personal and I perceived it as more genuine than the phone interviews. I feel this is especially beneficial when undertaking interviews about an issue which is as consciousness-raising as disability. An interview on this subject matter can obtain the best results when undertaken in a more personal style (as defined by Drew, Raymond & Weinberg, 2006). Another reason I may have felt that this style of interview to be the most valuable is defined by Yanos and Hopper's (2006) paper. They talk of a phenomenon that Erving Goffman coined 'Impression management'. This occurs when people make constructions of what they want others to hear, and therefore the way they wish to be perceived. As Interviewee C and I had made previous correspondence via email and phone to organise the interview, combined with the face-to-face

⁴Questions for Practitioners can be found in Appendix D, and questions for Policy makers in Appendix E.

nature of the interview, our rapport was stronger than with my other interviewees and Interviewee C's use of 'impression management' was reduced. I feel that he felt more obliged to answer my questions as he truly felt than if the interview had been on the phone (Warren & Karner, 2010, pp.161-164; Denzin & Lincoln, 1998; Schostak, 2004, p.125). Drew, Raymond and Weinberg (2006) also state that an interview is a period of social interaction which is sometimes not acknowledged by the researcher. Often an interview is seen as a passive information exchange process by the researcher (Drew et al., 2006). The social interaction that takes place in an interview, even a phone interview, allows much more analysis than passive information transfer might suggest, which allows the researcher to make interpretations which are not purely from the information being shared. The suggestions I made throughout the interview, the knowledge of the interviewees that I had a disability and talked about it freely making it a non-taboo subject, and the way that my interviewees responded, suggested that there were issues other than what they were verbally communicating, which was a benefit to the interview process.

When introducing myself at the start of the interview, I made certain that the interviewee knew I had a disability and also that I had completed my diploma of Public Health. This was both enabling and constraining in the interview process. I did this as I felt it would make the interview more relaxing as interviewees realised that I was not just intellectually attempting to understand the barriers that were posed for people with disabilities, but instead had a first-hand view, which I felt was a beneficial precondition to the conversations. However, this attempt to put my interviewee at ease may have also hindered the interview process. Broom, Hand and Tovey (2009) report on differing comfort levels of females with different gendered interviewers when talking about cancer care, work and family, and parenting. Similar to the interviewers reported on in this article, my positioning may have worked conversely for me as well. As all the respondents knew that the research concerned disability, they would therefore have been particularly politically correct when talking about the subject and their responses may not truly reflect the way they felt. In this introduction, I also attempted to establish rapport by asking trivial questions about their day, and the weather. I stopped asking these questions only after I was sure that the interviewee was relaxed enough to answer my interview questions openly (Denzin & Lincoln, 1998, p. 355).

Two of the interviewees had been out of the HIA field for over five years and identified that they may have forgotten much of their HIA experiences, which potentially may have made their interviews less valuable than they might have been. The place and time I performed the interview

affected the quality of the interview. When I conducted it out of formal university hours, I obtained a much better interview than when I conducted the interview in the administrator's office during the lunch hour, as there were more interruptions from students, and noise of the photocopier. This may have affected my own concentration and interrupted my thought process during the interview (Neuman, 2006, p. 362; Warren & Karner, 2010, pp.145-146).

Similarly, the technical faults that I faced on more than one occasion using the Dictaphone were a major hindrance to my ability to stay focused on the direction I was heading with the interview. This was a limitation especially in one informant's interviews where it happened on two occasions (Warren & Karner, 2010, p.148). Interviews were recorded by a Dictaphone, to be transcribed. Drew et al. (2006) point out the benefits of a tape recorder: "Tape recorders can record the respondents words with greater accuracy than can be achieved through note taking. Taping interviews also relieves the interviewer from having to take shorthand paraphrased notes of what they hear" (Drew et al., 2006, p.36). Transcription of interviews can also pose a hindrance to the interview process, as it is very difficult to perform a perfect transcription (Schostak, 2006, p.53). As I did not transcribe these interviews myself, there is an element of trust in those who performed the transcription that they did this as accurately as possible (Warren & Karner, 2010, pp.171-172).

3.5.5.3 Analysis of interviews

Firstly, each interview was presented in a narrative form. The analysis was done in two parts:

- a. A thematic analysis of the interviewee's explanations of the barriers impairing disability recognition in the practice of HIA in New Zealand and classified into two sets of categories which corresponded with the first two bodies of literature reviewed in the preceding step.
- b. Using the findings from the thematic analysis and responses from the interviews, I was able to create a meta-analysis which potentially underpinned all the presented barriers presented and allowed me to arrive at the conclusions of this study.

Transcriptions of each interview were initially written into a narrative specific to each interviewee's responses to the conversations we had engaged in (Warren & Karner, 2010, pp.229-233). The purpose of this narrative was to give an understanding of the nature of the way

the particular interviewee responded to a range of issues. These responses may give some indication into the relationship between HIA policy and practice concerning disability as it is perceived by that particular interviewee. One of the informants did not express any views in his interview, and therefore this interview was deemed insignificant to this research and omitted from the analysis.

Thematic analysis

Following this, I performed a thematic analysis to understand what the barriers were that the HIA actors gave to explain the poor awareness of disability issues in HIA Practice. To do this, I extrapolated any responses from the interview concerning the explanations of the observed relationship between policy and practice concerning disability in the HIA in New Zealand that the interviewees had defined. These were grouped into themes using a coding system (Neuman, 2006, Ch. 17; Denzin & Lincoln, 1998, p. 827). The rest of the analysis was put into an appendix as the rest of the conversation covered many different topics which may be of value to research conducted at a later date.

In their book *Analysing Qualitative Data* (2010), Bernard and Ryan define eight main techniques to recognise 'themes' in an interview. The first technique they talk about is perhaps the most obvious. It is identifying 'repetitions' (Bernard & Ryan, 2010, p. 56). When an interviewee repeats the same idea many times, it may be because this idea is a theme in the interview. The second technique they point to is locating 'indigenous typologies' or 'categories' (Bernard & Ryan, 2010, p. 57). This means looking for unfamiliar local lingo which is used in the conversation or common words used in unusual ways. This is often a signal that a specific theme is being talked about. Thirdly, Bernard and Ryan talk about 'Metaphors and Analogies' (p. 57) being indicators of specific themes. When people express a thought through a metaphor or analogy, this may be motivated by an underlying theme. The fourth reason they point to is 'transitions' (p. 58). They explain that themes may be marked by natural developments in conversation. Fifthly, Bernard and Ryan talk about 'similarities and differences' as indicators of specific themes (p. 58). Using this technique requires analysis of each sentence in the conversation, and subsequent identification when the subject matter changes as this could be a new theme. Sixthly 'linguistic connectors' (p. 60) are defined as a method of recognising a theme in a conversation. Identification of 'causal or conditional relations' (p. 60) that may be expressed as 'this happens because *this* happens', or, 'if this is so, then *this* must be so', and may indicate a thematic article.

Seventh, 'missing data' (p. 62) is a different way of identifying themes. Dissimilar to most techniques that look for the presence of a linguistic article, this technique looks for the absence of expected data. This is often an indicator of a theme. Lastly, Bernard and Ryan talk about 'theory-related material' (p.62).

Bernard and Ryan (2010) identify "social conflict, cultural contradictions, informal methods of social control, things that people do in managing interpersonal social relationships, methods that people ascribe and maintain perceived or ascribed status. And information about how people solve problems" (pp.199-200). These are all examples of theory-related material categories which could indicate the presence of a theme in a conversation.

The themes identified via the occurrence of repetitions in this research were:

1. HIA practitioner's personal experiences and understanding of disability
2. Decision over who gets scoped in HIA Process
3. Disability Advocacy
4. Lack of Social Awareness
5. Inappropriate consultation

The purpose of the thematic analysis in this research was to understand what the main barriers to the practice of the HIA guidelines were that each interviewee identified, consistent with the literature around the potential limitations to the assessment of disability issues in HIA policy (Neuman, 2006, Ch 17; Denzin & Lincoln, 1998, p.827).

These themes were then presented in a table with categories representing two of the three bodies of literature explored in chapter six. These categories were 'attitudinal barriers faced by people with disabilities' and 'generic barriers to HIA'. As none of the responses that the interviewees gave alluded to the third 'feminist interpretations of the constructions of disability' literature being an explanation of the questionable consideration of people with disabilities in HIA practice, I presented an argument that all the identified barriers are potentially underpinned by the barriers at meta level which constituted the 'feminist interpretations to the construction of disability' literature.

Creating a potential meta level analysis

Feminist interpretations of the construction of disability arguably underpinned both sets of barriers to disability recognition in HIA practice in New Zealand.

The themes supported by their verbal quotes obtained from the interviews were presented again, with a feminist construction of disability explanation as a meta-analysis. This explanation could potentially underpin all the verbal reasons that were presented in the table. This analysis allowed me to conclude that the factors influencing the barriers to disability recognition in HIA practice in New Zealand were borne out of social constructions of people with disabilities (as defined by the social model of disability) and could only be mitigated through institutional change.

3.6 ETHICAL ISSUES

The main ethical issue that I encountered was confidentiality issues due to the small and relatively well-known group of New Zealand HIA experts that I interviewed. Their stories and experiences specific to each interviewee made it easy to decipher which person the conversation was with.

In order to address this, I sent each person a transcript of their interview and asked them to approve it, and to take out anything they did not feel they wanted to be read by the public. The Canterbury University ethical guidelines also state that interviews with any government employees are classified as public information and therefore should raise no ethical concerns. Some of the experts I interviewed were in this position.

3.7 A CRITIQUE OF THE RESEARCH DESIGN

In hindsight, a bottom-up approach to understanding disability awareness in HIA practice, in conjunction with the top-down approach, gave me a comprehensive and critically informed insight into the dynamics of HIA policy and practice (Sabatier, 1986). I felt a combination of these methods was the most appropriate strategy to investigate my research questions. It provided me with an understanding of the effectiveness of the HIA policy from two perspectives, as further explained below.

The top-down quantitative analysis allowed me to gain a broad understanding of the level of awareness that New Zealand showed in disability awareness in HIA practice. This was very valuable as it allowed me to place New Zealand on a global continuum of disability inclusion in HIA with England, Scotland and Australia, and it also allowed me to tentatively hypothesise the reasons for the observed phenomenon. However, the value of this analysis was limited in terms of proposing a hypothesis, and verification of the reasons for the observed phenomenon. To do this, I needed to deploy a different method of research. This was done via the literature review which provided me with hypotheses to explain the observed phenomenon, and then a bottom-up, qualitative approach to analyse the HIA policy, which left me with a richly informed insight into the relationships, priorities, values and perceptions of key stakeholders involved in HIA practice.

3.8 REFLECTIONS ON THE RESEARCH: MY PERSONAL DISABILITY JOURNEY

During this academic inquiry into disability I have also undergone a personal journey. My own experience has had a large impact on the way I have understood disability in this research. Initially, my understanding of disability straddled at some point between the medical and social model, with a larger part towards the medical model. This is how I have been treated throughout my life as a disabled person and I assumed that this was the same for others with disabilities.

This research has made me realise that the experience I have had of disability has been unique. The beginnings of my disability resulted from a brain injury I obtained through a coma. The drugs that medical professionals administered to me were the first intervention that allowed me to gain consciousness and stop the inflammation in my brain. Although the results of my brain injury were horrific, the nature of the injury left me with the ability to rehabilitate with the help of therapists, and regain much of the function I had 'lost'. I still have a very strong belief in rehabilitation, which is a process defined by the medical model, and frowned upon by the social model. Though I have pushed the rehabilitation process of every function that was lost in the injury, I have not been able to regain all function, and face permanent impairments to my sight and balance. During the early days of my injury I understood disability explicitly in the medical model of disability, and I feel that the way I was treated was the most beneficial way for me to make the greatest gains, to reach my potential.

I feel that the age at which I obtained my disability has also been important to my understanding of disability. By the age of 16, I had already developed enough self-confidence and assurance to regard any stigma and discrimination based on my permanent impairments from anyone in able-bodied society as a product of ignorance on their behalf. Also my appearance has not been vastly affected by the disability I have. Unlike some of my colleagues who have Cerebral Palsy, or Downs Syndrome and are visually obviously disabled, I still look mainstream, even though I have impairments. In some ways, these factors have allowed me to effectively sidestep the overt attitudinal barriers that many people with disabilities face. I also have a family who support every goal I have. Though it has been a big struggle, I have achieved many things which one would have thought would have been too difficult – even impossible – when I first left hospital. I feel the support I have had from my family and friends has been a key factor which has meant that I have not seen myself in the medical model of disability, as I have felt empowered and in control of my life, with support from other people.

I still, however, face underlying attitudinal barriers which make everyday a challenge. Writing this thesis has been an exercise full of barriers. My access to literature has been very much hampered. Using the library to find books, and then reading those books has proved a task which I have not been able to do independently. Losing the ability to scan text has extended the time it has taken for me to finish this thesis. The copyright laws that I have had to grapple with have also made this thesis difficult. I am only allowed to reformat three percent of any book into enlarged text, which is the only way I am able to read any literature. This means that if the three percent I initially identify to enlarge is not the relevant part of the text, then I am prohibited from formatting any other part of the book. The support the disability resource service supplied me with in the form of a research assistant has made a major difference to these barriers, and allowed me to complete this work.

Throughout this research, my understanding of disability has increased in depth and I have gained greater insight into what living with a disability means. It has become increasingly obvious to me every day that the experience of disability that I have been through has been a unique one which I am very lucky to have had. The more I read, and the more people I meet, the more I realise that a majority of people with disabilities are prolifically disadvantaged by attitudes both overt and implicit. I realise the frustrations I face are only a grain of sand on a beach compared to the struggles and barriers others face. I see the way that the confidence of people can impair their ability and some are unable to speak up, or take opportunities to better their position in life.

Arguably, their participation in society relies on others inviting them to participate. It is obvious that these people need a spokesperson to advocate on their behalf. This population deserves every right that every other citizen has, and as life has already been made harder for them with their impairment, they should not be further disadvantaged by the cognitive blindness of those who control the policies that dictate their lives. It has become a lot clearer that there are many ways to make life more accessible for people with disabilities, which requires a basic level of awareness about this population.

Though I still feel that disability for me is not guided explicitly by the social or medical model, I feel that for a majority of people with permanent disabilities negative ramifications from treatment in the medical model of disability is a circumstance that they face on a day-to-day basis. I therefore feel very passionate that these circumstances are addressed and people with disability are allowed every right as the social model of disability defines.

CHAPTER 4: RECOGNITION OF DISABILITY IN HIA POLICIES FROM AN INTERNATIONAL PERSPECTIVE

4.1 INTRODUCTION

The first research question was defined in chapter one as follows: “How is New Zealand placed in consideration of people with disabilities in HIA policies and practices?” To answer the first part of this research question, I undertook a policy content analysis which interrogated the HIA policies of four countries, as explained in chapter three’s research methodology. The second part of the above research question will be addressed in the next chapter (chapter five).

In order to gain a broader understanding of where New Zealand sits in the broader context of disability inclusion in HIA policies, a policy content analysis was performed on a selection of HIA policy guidelines. The countries chosen as part of this research are comparable to New Zealand in several respects, including their common Anglophonic heritage and socio-political contexts. I analysed the HIA policy guidelines of England, Scotland, Australia and New Zealand by using the appropriate policy documents from each country. The policy content analysis involved an investigation of how many times each set of guidelines mentioned ‘people with disability’ as an important group to assess in their guiding procedures. As these guidelines are not written to focus on any particular disadvantaged population, but rather are written to guide practitioners how to carry out an HIA, I made the assumption that acknowledgement in the HIA policies that people with disability were part of the list of disadvantaged populations who were pertinent to the HIA, was adequate to remind HIA practitioners that this was a population that was worthy of their consideration. This chapter reports the research findings.

CHAPTER OVERVIEW:

Section 4.2 presents an overview of the scope of social policy in Western societies. This will outline how England, Scotland, Australia and New Zealand have all historically been characterised by the Welfare State and the ways they respond to social problems that are encountered in the respective countries.

Section 4.3 briefly explains from a similar stance the evolution of disability policies in these Western societies as above.

Even though these countries are broadly comparable, the extent of disability awareness in each country is, however, variable. Arguably, a significant factor in this phenomenon is the contribution of the ‘disability revolution’ in raising public awareness in each country (section 4.4).

Against the backdrop of the preceding sections, section 4.5 focuses on assessing the recognition of disability in HIA policies in Scotland, England, Australia and New Zealand. This analysis will be based on the most commonly used guiding procedures that each country has adopted for undertaking HIA.

Section 4.6 concludes by highlighting the key attributes of each country’s social and disability policies and relating them to the recognition of disability awareness in the HIA policy. Thus, this chapter will go partway towards addressing research question 1.

4.2 SOCIAL POLICY

Policy has many definitions, all of which take a slightly different perspective (Shaw & Eichbaum, 2008). Shaw and Eichbaum, in *Public Policy in New Zealand* (2008), give a selection of authors’ definitions including Dye (1972, p.5); “Policy is everything that governments choose to do or not to do”, and Peters (1993); “the sum of government activities that have an influence on the lives of citizens” (in Shaw & Eichbaum, 2008, p. 5). Bridgeman and Davis (2004) define policy as “an automotive response to a public issue or problem” (cited in Shaw & Eichbaum, 2008, p. 5). Policy definitions seem to encompass a specific action when governmental ideas are enforced and result in a change, which is known as policy action (Duncan, 2007). However, Heclo (1972) sees policy as a course of action or inaction, rather than specific decisions or actions (cited in Shaw & Eichbaum, 2008, p. 5).

Social policy is concerned with the way in which “well-being is influenced by the opportunities and resources available in society” (Cheyne, O’Brien & Belgrave, 2008, p. 1). Social policy includes a large range of interdisciplinary fields such as technology policy, recreation policy, health policy, economic policy, and environmental policy (Cheyne et al., 2008). Davis describes

social policy making as occurring in a “multi dimensional and multi-disciplinary manner” (Davis, 2007, cited in Cheyne et al., 2008, p. 5).

The social policies that guide a society are made by those in political control. These policies are shaped by many influences such as scientific evidence, experience, moral values and international circumstances. Together, these constitute a political ideology, or a set of ideas, that justify specific policies, and support the social and economic interests of specific groups (Davis, 2007). Political ideologies usually take one of two forms:

- Normative: based on values about human nature, about how we should conduct our lives, and how we can make a better society; or,
- Politically motivated or underpinned by political interests, although there is usually an attempt to hide this (Cheyne et al., 2008).

Political ideology has a direct effect on social policy (Shaw & Eichbaum, 2008). Cheyne, O'Brien and Belgrave (2008) point out that although there are many similarities between the social policies in developed countries, the way that a country responds to an issue may be different, and this may be due to their political ideology.

Scotland, England, New Zealand and Australia were chosen to be part of the policy analysis that is presented in the next part of this chapter. This is due to their similar socio-political contexts and also due to the similar political ideologies that were prevalent when a majority of the HIA cases I investigated were completed. This means that these countries would be more likely to respond similarly to both the issues of HIA and disability.

4.2.1 SCOPE OF RECENT SOCIAL POLICY APPROACHES IN ANGLOPHONIC COUNTRIES

It is important to understand how different countries respond to the social problems that they face in order to appreciate the broader socio-political context of HIA. For this reason, I provide a brief overview of the ways England, Scotland, Australia and New Zealand approach social policy issues.

4.2.1.1 English and Scottish approach

The United Kingdom (UK) countries of England and Scotland have shared a common history in the provision of social policies. This is primarily due to the governance of Scotland by Great Britain as a whole, before power was recently devolved from Westminster to Edinburgh (Mooney & Wright, 2009). Even after this devolvement of power, Scotland retains many characteristics of English social policy (Mooney & Wright, 2009).

John Major was the Prime Minister of The United Kingdom from the early nineteen nineties to the mid- nineteen nineties. He ran a Conservative government. Many of his policies echoed that of his predecessor Margaret Thatcher, who also endorsed social policy from a conservative perspective. Her primary aim was to keep public expenditure of health and education under tight control (Lund, 2008). This involved wide-ranging reforms for healthcare, education, social services, and housing. All of these radical changes were further endorsed when John Major took office (Beresford, 2001).

However, Major and his conservative ideology were succeeded by a new Labour government with a new political ideology. In 1997, Prime Minister Tony Blair was elected to office. He endorsed a Third Way government in response to the conservative policies that both Thatcher and Major had implemented (Lund, 2008). This new government was guided by an ideology that straddled between the post-war Welfare State and the previous Conservative governments (Lund, 2008; Giddens, 2001).

In his paper, “Major, Blair and the Third Way in Social Policy,” Lund (2008) gives a broad overview of the major themes that dominated government approach during Tony Blair’s time in office. Blair reformed social security services, catering for the under-represented in the labour market such as the over 50’s, under 25’s and people with disability. Help was offered in the form of preparation for work, help finding work, and sometimes training specific to jobs (Lund, 2008).

In education, Blair increased competition by devolving power from local authorities to parents (Beresford, 2001), giving them the autonomy to set up new schools. This increased access for disadvantaged children to gain admission into a good school (Lund, 2008). Healthcare also underwent reforms as Blair emphasised competition between healthcare providers by widening

the choice of providers that could be funded by the National Health Service (National Health Insurance scheme) (Lund, 2008). This increased access and choice for all British citizens regardless of their income. Housing was also reformed, but this occurred much later than the other social reforms listed above. Blair primarily used the 1996 Conservative White Paper to formulate his policies. It was not until 2003 that Blair started to exclusively attend to housing under his own political ideology (Lund, 2008).

During the time of Blair's governance, Scotland was also centrally governed from Westminster. Many of the policies that have been described above would also have been endorsed in Scotland.

All the UK HIA reports that have been analysed in this research (see chapter five) were prepared during the period of Tony Blair's government. As noted above, during Blair's government, the focus was on the social needs of the population. Hence, it could be presumed that disability awareness was high on the agenda of issues that needed consideration. As HIA is a tool to help endorse equality within society, it would presumably have been perceived as a valuable instrument.

4.2.1.2 Australian approach

Australia has faced a set of challenges in its provision of social policies. These have gained importance since the 1980's in response to conservative terms of government, during the time when the market was opened up and global forces increased poverty and inequality in Australia (Shaver, 1999). Despite the opening up of the economy, during the 1980's Australia maintained its Welfare State where provisions were made by the government to respond to a majority of needs (McClelland & St John, 2006; Shaver, 1999).

More recently, Australia has adopted the Third Way. As noted above, the Third Way does not endorse the Welfare State ideology or the neo-liberal ideology, but embraces the theoretical position which straddles the two (Giddens, 2001). From 1996-2004, John Howard followed a conservative variation of the Third Way ideology while in government (Saunders & Eardley, 2008).

In his 2005 paper "A decade of social policy under John Howard: social policy in Australia," Ryan defines five major themes which he believes are important in characterising this government in terms of its social policy provision. Firstly, he comments that "successive Howard conservative governments have been consistent in promoting conservative moral

values” (p. 455). These values have been proliferated in the form of increased government support of private institutions such as hospitals and schools that promote Christian values. Also, Howard made policies to mainstream indigenous programmes, and introduced a paternalistic model when understanding indigenous cultures (Ryan, 2005). This was a very conservative approach to the Third Way ideology.

Secondly, Howard asserted state authority over the existing pluralist methods of governance. Howard reoriented much of the power away from state government and centralised it to the federal government, and endorsed the defunding of organisations who refuted these methods of governance (Ryan, 2005)

Thirdly, Ryan (2005) explained that an important theme running throughout John Howard’s terms in office is that this was a time when market economics have dominated social policy. Many issues that this government dealt with were social issues that had an economic underpinning, such as the deregulation of the labour market which contributed to wage inequality.

Fourthly, this government promoted individual responsibility as a means to justify the retreat of the state from many areas of service delivery. This emphasis on individualisation was seen as cuts to funding for many parts of social welfare, including the dole, provision of money to single mothers, and people with disabilities. Perhaps the most adverse impact that Howard endorsed was the cut to services for the indigenous population. Howard refused to say ‘sorry’ to the Stolen Generation for historical ill-treatment of Aboriginal people by the government, and proceeded to cut their welfare funding. He justified this as providing them with motivation to increase the capacity to provide for their own welfare (Ryan, 2005; Saunders & Eardley, 2008).

Lastly, the Howard Government can be characterised by the mainstreaming of social policy. Terms such as gender disadvantage were replaced with individual responsibility. Words such as ‘equal opportunity’ and ‘equity’ were replaced by ‘diversity management’ (Ryan, 2005).

These characteristics promote a culture that sees people who have a disadvantage, like those with disabilities, as not being a responsibility of society as demonstrated by the cuts in welfare benefits for this group. Under these circumstances, the HIA would also not be expected to constitute a document of high importance in this society. However, as there is still a commitment to Welfare State provision, it would be assumed that the HIA would be considered a valuable tool.

All the Australian HIA case studies analysed in this research are from the period of the Howard government.

4.2.1.3 New Zealand approach

In New Zealand, in common with Australia and the UK, social policy has been impacted by the structural adjustment changes of the mid-1980's (Cheyne et al., 2008; Shaver, 1999). Social policy became progressively more important in this period as the increased privatisation and opening and growth of the economy led to greater competition. This meant that unemployment, poverty, lack of services and less access to services, especially by those who could not afford them, was increased. Following these changes, New Zealand took the shape of what has been called a reluctant Welfare State (Cheyne et al., 2008). During Labour's terms of office there was a reinvestment in social policies to address inequalities in the population (Cheyne et al., 2008).

Post the 1990's, there has been a change in ideology for New Zealand's government to the Third Way under the Labour-led Clark government from 2000 to 2009 (Giddens, 2001). As discussed earlier, this policy perspective straddles between the neo-liberal economies and the Welfare State, promoting both private and state ownership of assets (Saunders & Eardley, 2008). The Clark-led Labour coalition Government had a liberal view of this Third Way ideology. The state changed from a bureaucratic to a management paradigm (Pollitt, 1984; Kettl, 1997). Social policy was high on their agenda, and the government strove to take a holistic view of policies. They worked to fix fragmentation between the different ministries, who historically worked in 'silos', and changed their style to a 'whole-of-government' approach (Cheyne et al., 2008).

One way they did this was to ensure the ministries were aligned to the long term goals that government sought for New Zealand. This was carried out with a number of strategy documents including the New Zealand Health Strategy, the New Zealand Transport Strategy, the New Zealand Injury Prevention Strategy and the New Zealand Disability Strategy. These strategies have made it mandatory that each ministry report back every year on the ways which they have taken into account in their work the aims of the strategy (Cheyne et al., 2008). One step in the acknowledgment of disability was the voting in of the New Zealand sign language as an official language of New Zealand on April 6, 2006 (Dyson, 2006).

More recently, a new National government has come into power in New Zealand following the 2009 elections. This National government has taken a more conservative approach to the Third

Way ideology that Labour had adhered to. Anecdotal evidence would suggest that this government places more emphasis on the individual as opposed to the state. This can be seen through the proposal to privatise some ACC services and the downsizing of Public Health Units (Pers com, Margaret Earle, April 2011). The Minister in charge of Disabilities, Tariana Turia, has pushed hard for fiscal commitment by the government for those with disabilities (Pers com, Ruth Dyson, April 2010, Minister of Opposition on disabilities). Dyson has been quoted as saying that she feels that [though] “Tariana Turia gets it, she has no influence... because she is outside the National Party it is really hard for a member of a small party who are already pushing for a lot of other things to get progress on advocacy work” (Pers com, Ruth Dyson, April, 2010).

The characteristic policies of Labour’s coalition government that have been described above would lead one to expect that both needs of people with disabilities and HIA would be considered as legitimate government objectives. All the New Zealand HIA case studies analysed in this research are from the period of the Labour government that has been described as Third Way.

4.2.1.4 Concluding comments

The above investigation into the ways that England, Scotland, Australia and New Zealand respond to social issues has demonstrated that these countries have comparable ways of responding to wider global economic imperatives that impact on social policy, with some differences in terms of socio-economic priorities.

4.3 DISABILITY POLICIES IN THE UK, AUSTRALIA AND NEW ZEALAND

It is also important to understand the ways in which the four countries involved in this analysis, Scotland, England, Australia and New Zealand, have specifically responded to the needs of people with disabilities. This section provides a brief overview of their responses, followed by a discussion of the role of the Disability Rights Movement in shaping these policies.

4.3.1 UK DISABILITY POLICY

As explained above, Scotland and England have a similar approach to social policy. This is due to the British rule of both Scotland and England as part of the United Kingdom. After the devolution of 1997, Scotland’s approach to social policy has been described as socially innovative

in comparison to the characteristic welfare-based policies of England (Mooney & Wright, 2009). Arguably, this is also evident to some extent with disability policies, as shown below.

As explained above, the United Kingdom has historically been characterised by the Welfare State which came about due to the failure of free market economics in the late nineteenth and early twentieth centuries. This approach was further endorsed by the political and economic uncertainty that was brought about after World War II (Barnes & Mercer, 2006). The Welfare State was characterised by policies that catered for disadvantaged groups such as children, elderly, mentally ill and people with disabilities (Barnes & Mercer, 2006).

One of the first comprehensive Acts that was passed to cater for people with disability was the *Disabled Persons Employment Act* 1944, which aimed to secure employment rights for disabled people (Barnes & Mercer, 2006). However, this Act failed in achieving its objectives to find employment for people with disabilities, and seemed more concerned with ensuring that employers were not upset with the ‘demands’ that people with disabilities placed on them (Oliver & Barnes, 1998).

This Act signalled a new government philosophy to cater for people with disabilities, and so began the attempts of the Welfare State to make provision for people with disabilities (Oliver & Barnes, 1998; Barnes & Mercer, 2006). By the late 1950’s, the government realised that even though its attempts to cater for people with disabilities were expected to be inclusionary, this was not happening in practice (Oliver & Barnes, 1998). For example, one way the government attempted to be inclusive was by reducing the number of people living in segregated institutions. However, this resulted in people with disabilities being isolated in ‘mainstream’ accommodation (Oliver & Barnes, 1998; Barnes & Mercer, 2006).

In 1962, the government released a plan called *Health and Welfare: The Development of Community Care*. The plan was developed to promote inclusion and reduce stigmatization of people with disabilities (Barnes & Mercer, 2006; Oliver & Barnes, 1998). However, for people with mental impairments, the term ‘Community Care’ is exclusionary in itself as it suggests life outside an institution, while still being taken care of by close neighbours and friends. This meant the implementation of this policy was not very clear or well understood. The struggle to rationalise it was coupled with the fact that the government had an overstretched budget due to increasing needs and expectations after World War II, and an increase in the number of dependants which included children, post retirees, and also disabled people (Barnes & Mercer, 2006). This resulted

in the government setting up an enquiry into how community care was being implemented. This inquiry resulted in further limitations on provision being made for local community-based services for people with disabilities (Oliver & Barnes, 1998).

The 'integration' rhetoric had little effect on improving the lives of people with disabilities. This resulted in another review of welfare-based services in the 1980's (Oliver & Barnes, 1998). The review signalled that the ideology of the post-war Welfare State was breaking down as new ideas about service provision for people with disabilities came to light.

These new ideas involved a strategy that stimulated private and voluntary sectors to provide for people with disabilities. This took the onus off the government as the only purveyors of disability services (Barnes & Mercer, 2006). The government also hoped that this increased choice would lessen the dominance of professionals and the dependence of people with disabilities. However, this did not happen and people with disabilities were of the view that 'this change in legislation has not changed the balance of power' (Oliver & Barnes, 1998, p. 41).

Post 1990's, people with disabilities still feel that professionals hold an unequal balance of power in service provision. Though many of these people go by different job titles, the problems still exist that have historically faced people with disabilities.

One thing, however, which has changed, is the discourse that surrounds disability. This discourse has changed from the service-provision, individualistic model, to a model based on the formation of disability being placed squarely in the hands of society, and if it is to be attended to, it needs to be addressed at a societal level (Barnes & Mercer, 2006; Oliver, 1998; Barnes et al., 1999; Campbell and Oliver, 1996; Oliver and Barnes, 1998).

4.3.2 AUSTRALIAN DISABILITY POLICY

In the 1940's and 50's in Australia, many small organisations evolved to cater for people with specific disabilities. These organisations were totally dependent on charity for their income. For example, an annual fundraiser was the telethon beauty pageant which supported disability organisations (Disability Services Australia, 2007).

As people with disabilities were segregated from mainstream society, some organisations set up special workshops and other services for people with specific disabilities. For example, a TB

Association created wood-working workshops for eight men who had tuberculosis, and the Crippled Children's Association started a school for children with Cerebral Palsy (DSA, 2007). Post World War II brought the return of many soldiers who had fought in the war and sustained some sort of sensory loss. In 1957, guide dogs began to be trained to support those with visual impairments (DSA, 2007).

In 1967 the government adopted the language of 'normalisation'. In an effort to promote this, the Commonwealth Government of Australia passed the *Sheltered Employment Assistance Act* 1967, which provided assistance for non-profit organisations to make provisions for sheltered employment. A Sheltered Employment Allowance was also introduced, and means-testing forced a cap on the wage that could be earned by people with disabilities (DSA, 2007). These changes were fuelled by the newly emerging human rights discourse.

The year 1974 brought a change in the school of thought about the way people with disabilities were catered for in Australia, and subsidies for people with disabilities were increased. Organisations which provided rehabilitation and therapy services were subsidised as it was felt that people with disabilities would fit into the 'mainstream' if they underwent this training (DSA, 2007).

The years 1983-85 brought yet further policy changes when people with disabilities were 'mainstreamed'. This was marked by the *Disabled Services Act* of 1986, which encouraged open employment. With this change, there was also the disestablishment of segregated sheltered workshops. Also in the early 1980's, the change of rhetoric could be seen in the form of new schools being set up, and the renaming of several organisations. In 1982, the Australian Wheelchair Sports Organisation was set up (DSA, 2007).

In 1984, the *South Australian Equal Opportunities Act* was set up to ensure that people with disabilities did not endure discrimination based on their disability. This was followed in 1986 by the formation of the Equal Opportunities Commission who investigated any cases where people had been discriminated against based on their disability. In 1987, this Act was further extended with the *Equal Opportunities in Employment Act* which specifically ensured people with disabilities were not discriminated against based on their disability in employment (DSA, 2007).

The year 1992 brought further legislation to remedy the unequal status of people with disabilities in the formation of the *Disability Discrimination Act*. These principles were further endorsed with

the increased provision of formal opportunities and legislation for people with disabilities, and the recognition of their many talents (DSA, 2007).

The 2003 Australian census estimated that 20 percent of people in Australia have a disability. This estimate has been the basis for plans to provide services for people with disabilities (DSA, 2007).

4.3.3 NEW ZEALAND DISABILITY POLICY

During early European migration to New Zealand, the government discouraged people with disabilities to undergo resettlement. The *Imbecile Passengers Act* of 1882 charged the owner of a ship if they were carrying a ‘lunatic, idiotic, deaf, dumb, blind or infirm’ passenger, who may have to be catered for by a charitable institution (ODI, n/d).

At the turn of the twentieth century, methods to identify and ‘appropriately’ attend to ‘defective’ children meant that those with any impairment, especially a ‘mental’ impairment, were institutionalised (ODI, n/d). This was further endorsed through specific organisations such as the Tuberculosis and Amputees associations being set up to cater for specific disabilities. These organisations had very little government support (Moore & Tennant, 2007; ODI, n/d).

In 1938 the first Labour government came into power heralding the beginnings of New Zealand’s characteristic Welfare State, which made provision for all people including the poor, old and those with disabilities. This came largely in the form of sheltering people with disabilities in special schools and workshops or segregated residential care facilities. This help was largely charity-based with an overwhelming view of people with disability as a ‘helpless’ population who needed to be taken care of, and were not capable of making their own decisions (Cheyne et al., 2008; Moore & Tennant, 2007; ODI, n/d).

By the 1950’s, the government had changed their view of people with disabilities. Instead of a paternalistic approach, the government now advocated an approach that endorsed ‘normalisation’ and ‘integration’ (ODI, n/d; Moore & Tennant, 2007). This involved medical rehabilitation of people with disabilities, and a push for them to live as ‘normal’ people. This change was partly in an effort to cater for returned ex-servicemen from World War I, and

allowed impaired soldiers to return to work in sheltered workshops (ODI, n/d; Moore & Tennant, 2007).

In 1975 the *Disabled Persons Community Welfare Act* was implemented. This Act aimed to provide support for those who were disabled to live as ‘normal’ people in the mainstream community as opposed to concealing them in residential homes (Saucier, 2002; ODI, n/d; Moore & Tennant, 2007). This major policy shift was eventually implemented into education, with blind children being integrated into mainstream classrooms in 1980 (Moore & Tennant, 2007).

Arguably, the most influential practice that characterised the 1980’s period of ‘integration’ was the move to deinstitutionalise people with disabilities and the disestablishment of most residential care facilities. Although this change was a great improvement on the way that people with disabilities had previously been viewed, it still recognised disability as an individual affliction, and did not accept that disability was a social construction (Beatson, 2001).

The year 1990 brought yet another change in policy – the transformation of the rehabilitation Act to Workbridge; a government run agency that supports people with disabilities in finding work (ODI, n/d; Beatson, 2001; Moore & Tennant, 2007).

The year 2001 heralded an exciting change of rhetoric from the medical model to the social model. This was proliferated in the form of *The New Zealand Disability Strategy* 2001 (ODI, 2001), which is an example of the social model of disability in the New Zealand context. This commitment to disability has been endorsed with the adoption of sign language as an official national language of New Zealand in 2006. New Zealand also displayed a dominant role in the negotiation of the United Nations *Convention on the Rights of Persons with Disabilities* (2007) and shortly after, in 2007, signed up to it.

4.4 THE ROLE OF THE DISABILITY RIGHTS MOVEMENT

The Disability Rights Movement has been a significant factor in raising public awareness of disability and shaping government policies through advocacy. The beginnings of the era of liberalisation, and the push for free thinking brought by social movements, begun in America post World War II. This was characterised by the Black Civil Rights Movement. However, this fight for rights quickly spread to the Women’s Movement, environmentalism, and anti-Vietnam

protests. The Disability Rights Crusade also began here (Beatson, 2001; Bryan, 2000; Bailey, n/d).

The Disability Rights Movement

Beatson (2001) writes in his book *The Disability Revolution in New Zealand* that there are four characteristics of the movement that are not dependant on where in the world it has taken place.

These are:

- the move from charity to rights,
- the demand for partnership or control in their own organisations
- the development of a pan-disabled consciousness
- internationalism

The move from viewing disability from a charity to a rights-based model is perhaps the most important principle of the disability movement according to people with disabilities. This principle has implications for every part of life for a person with a disability. People with a disability have historically been treated like ‘helpless victims’; unable to make their own decisions, as defined by the medical model of disability. People with disabilities wish to be treated like citizens, equal to the able-bodied population. This means they deserve the same rights, respect, autonomy and equality as any other sector of society (Oliver & Barnes, 1998; Beatson, 2001).

Able bodied people have historically controlled the lives of those with disabilities, as they have felt that disabled people have little ability to identify what they need in their lives. The disability movement advocates that people with disabilities should be in partnership with the able bodied community, if not in full control of their own organisations. They reserve the right to autonomy to achieve their own hopes and dreams. It makes little sense for those who do not face the social, cultural, physical and psychological barriers that people with disabilities face to dictate the lives of those with disabilities (Beatson, 2001; Oliver, 1998).

However, the voice of the ‘disabled message’ has been fragmented and weakened. One of the reasons for this is because historically, two groups have headed the disability movement. These are the blind and wheelchair users. These groups have been known to focus on their own

impairment as opposed to the 'disability rights awareness message'. The result is in an uncoordinated and potentially diffused disability rights message. There needs to be an endorsement of a pan-disability solidarity movement, to push the principles outlined in this review (Beatson, 2001).

The last of these principles that is promoted in all Disability Rights Movements regardless of where they have globally originated is the need for the building of more international links and relationships with other people with disabilities across the globe. The global consolidation of people with disabilities would give a stronger, more mainstream voice to the message of disability rights, and increase disability awareness (Beatson, 2004; Driedger, 1989).

The Disability Rights Movement, though a global movement, has been expressed differently in all countries around the world. In the United Kingdom, it was marked by radical protest, fuelled by the group UPIAS (the Union of People with Impairments Against Segregation) formed in the mid 1970's. This involved acts of passion such as individuals chaining themselves to buses. Wheelchair users would file lawsuits when airlines would not allow them to board flights, and in America, there were pickets at the White House and federal buildings in the name of disability rights (Stoddard, 2002; Pers com, Steven Daw, Feb 2011). The protests in the United Kingdom have had a very high public profile. Arguably, this may have lead to the government in the United Kingdom making people with disability a priority in legislation.

In Australia, there was also activism to promote the rights of people with disabilities. The most public of these was the lobbying against the Miss Australia Quest and the redirection of its proceeds to disability organisations, the manipulation of the Home Accommodation Support Scheme to include fully subsidised attendant care, and the abolition of institutions and subsequent re-housing of people with physical impairments from hostels and nursing homes to community housing. Mental Health was also lobbied for through the formation of state-wide advocates, guardianship, and administration boards. As there are many disability organisations in Australia as defined by the disability policy review above, these acts of protest were run by the most prominent organisations that were closest to the sectors that wanted change (Cooper, 1999; DSA, 2007).

The Disability Rights Movement in New Zealand involved court cases, lobbying and marches, but it has been a lot less public than in the UK and the USA (Pers com, Paul Dickey, Senior Policy Analyst ODI). Rhetoric also changed from an individualistic, medical model of disability, to a socially constructed model of disability. This can be seen in the *New Zealand Disability Strategy* (ODI, 2001), which makes a clear distinction between biological impairment and a socially constructed disability. However, there is no legislative consequence of not abiding by this policy document, and this may indicate that the government commitment to people with disabilities is also questionable.

In conclusion, although the disability policy history of the countries presented above has been broadly comparable, the prolife of the Disability Rights Movement has shown an incongruent distribution. This may aid in understanding why the disability acknowledgement in HIA practice (which is further explored in the next chapter) also shows a varied trajectory.

4.5 ANALYSIS OF DISABILITY RECOGNITION IN HEALTH IMPACT ASSESSMENT POLICIES

The Health Impact Assessment is an example of social policy; a tool that has been designed to assess the way that policy impacts on disadvantaged groups and allows policy makers to change their policies to mitigate any negative effects, as explained in section 2.2.3. As people with disability constitute a disadvantaged group, it would be assumed that the policy rhetoric in the HIA guidelines on how to perform HIA would have an adequate acknowledgement of people with disability as an important group that needs to be considered. This was investigated in a review of the most commonly used HIA guidelines of selected countries, as discussed below.

The specific countries England, Scotland, Australia and New Zealand are listed below with the frequency of disability inclusion of their HIA guidelines. As explained in chapter two, the information from the guidelines was sourced from publicly available government websites.⁵ The results are displayed in Table 4.1 below. The Scottish HIA Guidelines make no mention of

⁵England: The Merseyside Guidelines for Health Impact Assessment Scott-Samuel, A., Birley, M., Ardern, K., (2001). *The Merseyside Guidelines for Health Impact Assessment*; Australia: *Health Impact Assessment Guidelines*, Commonwealth of Australia, (2001); Scotland: Douglas, Margaret (2009), *How to do Health Impact Assessment: a guide for practitioners*, Scottish HIA Network; New Zealand: Public Health Advisory Committee, (2005), *Te Ropu Tobutobu i te Hauora Tumatanni, A Guide to Health Impact Assessment: A Policy Tool for New Zealand*, 2nd ed.

disability as a population that needs to be assessed in HIA practice. The Australian HIA guidelines mention people with disability once in their procedures. This is when giving examples of groups that need to be assessed in HIA practice. The English HIA guidelines mention people with disability once in their procedures as part of a table when talking about ‘Key areas influencing health’ and ‘wellbeing’.

Table 4.1: Mention of Disability in the HIA Guidelines of Scotland, England, Australia and New Zealand(snapshots of PDF versions of the guides)

1. HIA Country Guidelines	Disability Inclusion
Scottish HIA guidelines	No mention of people with disability

2. HIA Country Guidelines	Disability Inclusion
English HIA guidelines	One mention of people with disability, page 12 (see below, Figure 3). This occurs in a table when talking about ‘Key areas influencing health’ and ‘wellbeing’.

Figure 3 Key areas influencing health

Categories of influences on health	Examples of specific influences (health determinants)
Biological factors	age, sex, genetic factors
Personal / family circumstances and lifestyle	family structure and functioning, primary / secondary / adult education, occupation, unemployment, risk-taking behaviour, diet, smoking, alcohol, substance misuse, exercise, recreation, means of transport (cycle / car ownership)
Social environment	culture, peer pressures, discrimination, social support (neighbourliness, social networks / isolation), community / cultural / spiritual participation
Physical environment	air, water, housing conditions, working conditions, noise, smell, view, public safety, civic design, shops (location / range / quality), communications (road / rail), land use, waste disposal, energy, local environmental features
Public services	access to (location / disabled access / costs) and quality of primary / community / secondary health care, child care, social services, housing / leisure / employment / social security services; public transport, policing, other health-relevant public services, non-statutory agencies and services
Public policy	economic / social / environmental / health trends, local and national priorities, policies, programmes, projects

3. HIA Country Guidelines	Disability Inclusion
Australian HIA Guidelines	One mention of people with disability, page 6 (see below, Box 1) when giving examples of groups that may need to be assessed in HIA practice.

Box 1

Examples of potential health impacts that may need to be considered during HIA

General environmental aspects that may impact on health:

- Increased demand and/or improvements to public infrastructure (water supply, sewerage, waste management, health, education, other government services).
- Altered risk from acute hazards, eg. fires, spills during transport or handling of materials.
- Altered motor vehicle traffic leading to changed risk of injury or air pollution.
- Damage to vulnerable ecosystems that are of importance to human health.
- Impact on health or amenity through changes to odour, noise, dust, insects, shade, vibration, light spill, etc (including what are historically referred to as environmental health nuisances).
- Encourage/discourage healthy forms of physical activity eg. walking or cycling.

Potential impacts on physical health:

- Communicable/infectious diseases (eg. spread of STDs, mosquito-borne disease).
- Non-communicable diseases – cardiovascular disease, cancer, asthma, etc.
- Exacerbation of existing conditions.
- Injury, eg. from trauma.

Social impacts which have a health effect:

- Employment opportunities created/lost.
- Effect on local government revenues.
- 'Spin-off' effects on local industry.
- Changes in social conditions (way of life) or demographic changes leading to health consequences eg. the likelihood of changes to alcohol consumption in an area.
- Mental and emotional wellbeing of a community (eg. is the development likely to cause or allay stress, anxiety, nuisance, discomfort).
- Altered (improved or decreased) opportunity for recreation or socialisation.
- Increased or decreased isolation of individuals.
- Shifts of population into or out of the affected area and the health impacts of such shifts.

Special populations that may need to be considered include:

- the elderly;
- the disabled;
- persons of low socio-economic status;
- children – born and unborn;
- Persons with a non-English speaking background;
- Indigenous Australians;

Specific examination of the demography of the area under consideration may reveal other groups to be considered.

In this research, I have made the assertion that disability policy rhetoric in the New Zealand national HIA policy guidelines is comprehensive when compared with England, Scotland and Australia, all who have similar socio-political contexts.

In order to prove that the New Zealand policy frameworks surrounding disability are comprehensive, and that there seems to be adequate discussion of disability in written policy terms, I will critically analyse the New Zealand Health Impact Assessment Guidelines to understand how important an issue people with disability are perceived to be in this guideline.

The New Zealand HIA Guidelines cite disability eleven times in this guide as a group that needs to be considered in HIA practice: six times as a potential population that need to be assessed; twice as a specific question to be considered when undertaking an equity lens assessment (as talked about in the literature review); once as an example in the inequalities appraisal, and once in reference to the disability strategy.

The guidelines make reference to the social model of disability in the *New Zealand Disability Strategy* (ODI, 2001). The guidelines reflect the attributes of the social model with the inclusion concept, which is integral to the social model, being emphasised. This is important as it is the most current way to understand people with disabilities. (See below for snapshots from a PDF version of all eleven mentions).

4. HIA Country Guidelines	Disability Inclusion
New Zealand Guidelines	Eleven mentions of people with disability (see below)

Mention 1. Health Determinant and Health Outcomes

Examples of determinants of health that may be considered in applying the HIA Guide are:

- social and cultural factors (eg, social support, participation, access to cultural resources such as marae)
- economic factors (eg, income levels, access to employment)
- environmental factors (eg, land use, air quality)
- population-based services (eg, health and disability services, leisure services)
- individual/behavioural factors (eg, physical activity, smoking)
- biological factors (eg, biological age)

Mention 2 and 3. Appraisal and Reporting: Selected examples of Health Determinants

Table 3: Selected examples of health determinants	
Categories of determinants of health ²⁰	Examples of specific health determinants
Social and cultural factors	Social support, social cohesion Social isolation Participation in community and public affairs Family connections Cultural and spiritual participation Expression of cultural values and practices Links with marae or other cultural resources Racism Discrimination Attitudes to disability Fear of prejudice Relationship with the land and water Level and fear of crime Reputation of community/area Perceptions of safety
Economic factors	Creation and distribution of wealth Income level Affordability of adequate housing Availability and quality of employment/education/training Skills development opportunities
Environmental factors (including living and working conditions)	Housing conditions and location Working conditions Quality of air, water and soil Waste disposal Energy Urban design Land use Biodiversity Sites of cultural significance (eg, sacred or historic sites) A change in the emissions of greenhouse gases Public transport and communication networks Noise Exposure to pathogens
Population-based services	Access to, and quality of: employment and education opportunities, workplaces, housing, public transport, health care, disability services , social services, childcare, leisure services, basic amenities, and policing.
Individual/behavioural factors	Personal behaviours (eg, diet, physical activity, smoking, alcohol intake) Life skills Personal safety People's belief in the future and sense of control over their own lives Employment status Educational attainment Level of income and disposable income Stress levels Self-esteem and confidence
Biological factors	Biological age

Mention 4. Guidance to help identify health determinants

GUIDANCE

Guidance to help identify health determinants

Ask the following questions to help select the relevant determinants:

- using the table as a prompt, what are the main factors determining health that may be affected by this policy?
- what other determinants **apart** from those in the table could be relevant?
- how could the initial list of your determinants be grouped or summarised to produce a concise list of the **most** relevant determinants in this situation?

It is unlikely that the HIA will be able to cover all of the identified determinants of health in the next stage of the appraisal, so a decision on which determinants of health should be taken forward is likely to be required. Make a judgment on which ones affect the most people, affect vulnerable groups disproportionately, affect Māori, or are of concern to stakeholders.

Note:

- brainstorming/workshop approaches work well
- involve a range of people outside the policy development group such as social scientists, community workers, public health specialists, etc
- consider the objectives of the policy and its expected outcomes (identified in scoping stage)
- think about particular scenarios or possible impacts on particular groups (eg, women, Māori, **people with disabilities**, urban residents).

Highlight the chosen determinants in Table 3 to take forward to the impact assessment stage.

Mention 5. Health Lens Checklist

HEALTH LENS CHECKLIST

1. What are the potential impacts of the policy proposal on the identified determinants of health? (The determinants were identified earlier in the appraisal stage within the following groups)

- social and cultural factors
- economic factors
- environmental factors
- population-based services
- individual and biological factors

2. What are the potential impacts on health *outcomes*?

(Refer to Te Whare Tapa Wha model of health in the section 'What else do you need to know?' – ie, the four components listed. Also refer back to Question 1 to help answer this question. Consider each determinant in turn).

- physical health
- mental health
- family and community health
- spiritual health

3. How will the policy proposal address the principles of partnership, participation and protection? (Refer to the "What else do you need to know?" section for definitions).

4. What are any potential effects on health inequalities?

(Consider whether inequalities could be reduced or widened – refer to background section where there is an explanation of health inequalities. Who would be most affected?)

5. In particular, how will the policy impact on people with disabilities?

6. What might the unintended health consequences of the policy be? How will these be addressed?

Mention 6. Description of Impact: Impact on Māori with disabilities and their whānau/families

Questions:

- 1) How does the policy proposal provide for effective partnership with Māori? (the principle of partnership)

- 2) How does the policy proposal provide for opportunities for Māori to contribute to the policy process? (the principle of participation)

- 3) How does the policy proposal contribute to improved health outcomes for Māori? (the principle of protection). Please explain where it does or does not.

- 4) Considering the determinants of health in the previous section, what is the potential effect of the policy proposal on Māori health?

- impact on the mental and physical health and wellbeing of Māori whānau/families/communities

- impact on the spiritual and cultural values of Māori whānau/families/communities

- impact on Māori with disabilities and their whānau/families.

Mentions 7 and 8. Matrix for determinants of health (example: impacts of improved passenger transport)

EXAMPLE

Table 4a: Matrix for determinants of health (example: impacts of improved passenger transport)

Health determinants specific to policy (identified from table 3)	Description of impact on each determinant of health	Identify any measurable indicators ^{*1} or qualitative impacts ^{*2}	How measurable is the impact? ^{*3}	Differential impacts on particular groups with respect to each determinant	External influences that may interact with the policy being assessed	Summary of impact on each determinant of health (2nd column) ^{*4}
Social support and social cohesion	Improved availability of bus services enables people to be mobile and maintain social support networks	Qualitative information could be sought through surveys or interviews	Qualitative	Particular impact on people without car access, those on low incomes, older people, unemployed	Availability of alternative public transport More affordable cars	Positive
Air quality	Potential for improvements in air quality through reduced use of cars	Local air quality monitoring	Measurable	Particular impact on people with respiratory conditions, older people, children	Regional and national Air Quality Standards Vehicle emission standards	Potential positive impact over the medium to long term
Access to: – employment and education opportunities – health care, disability services, social services – facilities for people with disabilities	Timetable and routes affect access to public services	Qualitative information through surveys	Qualitative	Access to services, employment etc. for families/people without cars and people with disabilities	Availability of alternative public transport and of walking and cycling tracks	Positive
Physical activity	a) Increased physical activity through walking to bus stops/train b) Decreased physical activity if availability of new bus routes within a central city area means that people choose to take the bus instead of walking	Qualitative information through surveys	Qualitative	Not applicable	Walking and cycling policies of local authority	a) Positive b) Negative

*1 eg. unemployment rates, changes in income levels
 *2 eg. impacts identified from interviews with key informants, surveys or anecdotal information
 *3 classify as qualitative, estimable or measurable
 *4 positive, neutral or negative
 *5 these are grouped determinants, in this case arising from public transport

Mention 9. Questions to help fill out Table 4.

GUIDANCE

Questions to help fill out Table 4:

- In the first column, list the specific determinants of health relevant to the policy proposal that were identified from Table 3.
- Describe the impact of the policy on each of these determinants of health. Remember that you are considering impacts on **determinants** only (not health outcomes).
- What measurable indicators are available to substantiate the choice of each impact?
- To what extent can each impact be measured? (classify as either qualitative, estimable or measurable).¹³
- Will the policy proposal exacerbate or reduce health inequalities for any groups, with respect to each determinant? If so, in what way? **Consider Māori, low socioeconomic groups and people with disabilities in particular.**
- What other influences are there on the determinant of health? Are there other policies, legislation or interventions that may interact with the policy being assessed?
- In summary, is each impact positive, neutral or negative?

Mention 10. Inequalities appraisal

C) Inequalities appraisal

This section of the tool considers specifically the potential for the policy to have impacts on health inequalities. Inequalities in health occur across a range of areas, including socioeconomic status, age, gender, ethnicity, **disability** and geographic location. Note that one measure of socioeconomic status is the New Zealand Deprivation Index (NZDep), which takes the following variables into account:

- access to a telephone
- income including whether on a benefit or having an income below an income threshold
- employment status
- access to a car
- living in a single parent family
- educational qualifications
- home ownership
- living space.

These are all variables that have relevance when conducting a health impact assessment.

Mention 11. The New Zealand Disability Guidelines

One of the objectives of the New Zealand Health Strategy⁴ is to assess public policies for their impact on health and health inequalities. The New Zealand Disability Strategy promotes an inclusive society that enhances full participation by those with disability.⁵ Wide application of HIA will help to ensure the objectives of these strategies are met.

The eleven mentions of people with disabilities in this guide as an important population to assess should be sufficient to remind HIA practitioners that the HIA policy makers consider people with disabilities as an important population that needs awareness in the practice of Health Impact Assessments.

4.6 SUMMARY

The key findings of this chapter are as follows: England, Scotland, Australia and New Zealand have comparable social policy frameworks derived from the Welfare State model they have formerly subscribed to. These policies have been moderated by recent conservative and Third Way policy ideologies. Hence, the scope of their past and present disability policies is broadly comparable. Their current policies reflect the underpinnings of the social model of disability. However, the Disability Rights Movement may have been more successful in raising public awareness of disability in the UK as compared to New Zealand.

The Scottish HIA guidelines have no mention of people with disability as a population group that needs awareness. The Australian and English HIA guidelines cite disability once in their policy guidelines.

The New Zealand HIA guidelines cite people with disability eleven times in their guiding procedures. This is the most thorough disability inclusion of all the HIA guidelines after comparing references to disability in this international review. Also of notable significance is the reference this guide makes to the social model of disability in the form of recognition of the *New Zealand Disability Strategy* (2001).

The purpose of this document is not to emphasise the principles of the social model of disability, but rather to guide people who wish to undertake an HIA. However, through its inclusive

awareness of people with disabilities and also its reference to the *New Zealand Disability Strategy* (ODI, 2001) it makes a strong statement about the level of disability awareness of the HIAs that it guides. It also endorses the recognition that people with disabilities face wide-ranging societal barriers and that they should be empowered to exercise a proactive role in policy development. It would therefore be assumed that HIA practice would present with the same disability awareness.

In the next chapter, I will investigate the extent of inclusion of disability awareness in performed HIA case study reports in the four case study countries to see if the awareness of disability found in the policy guidelines is indeed translated into the practice of HIAs as presented in completed HIA case reports. The resulting policy/practice relationship, to be investigated in subsequent chapters, will suggest explanations of this relationship.

CHAPTER 5: CONSIDERATION OF DISABILITY IN HIA REPORTS

5.1 INTRODUCTION

The needs of people with disabilities are acknowledged differently in different countries. This is due to a combination of factors, as discussed in the previous chapter. Against the backdrop of this discussion, chapter five examines to what extent disability is recognised in recently-performed HIA case reports. This will be done by carrying out a quantitative top-down policy analysis of HIA case studies from selected countries, including New Zealand.

CHAPTER OVERVIEW:

- Section 5.2 summarises the literature on different methods of policy analysis. This sets the scene for the next section that analyses recent HIA reports from a top-down perspective.
- Section 5.3 looks at the implementation of HIA policy in the disability sector based on a quantitative analysis of internationally performed HIAs from Scotland, England, Australia and New Zealand. These results will be presented in tables. From this analysis, I hope to be able to ascertain how each country considers disability issues in the HIA process. I then hope to be able to place New Zealand on this continuum to give insight into how New Zealand practitioners of HIA view disability.
- Section 5.4 presents a summary of the research that was undertaken in this chapter accompanied by graphs to provide a visual representation. This will complete the examination of the first research question that this thesis seeks to answer: What is the relationship between policy and practice of disability awareness in HIA in New Zealand?

This chapter also provides a basis for the second research question, examined in chapter six: What are the explanations to assist in understanding the relationship between HIA policy and practice in the disability sector in New Zealand?

5.2 POLICY IMPLEMENTATION

Policy implementation can take place via one of two ways. In their early but still relevant book *The Policy Process in the Modern Capitalist State* (1984), Ham and Hill define two methods of studying policy implementation; the top-down, and bottom-up models.

The top-down approach assumes that there are two discrete stages involved in the policy cycle – policy formulation and policy implementation. Within this school of thought it is believed that by understanding the ways that the implementation of a policy has or has not met its goals in the implementation stage, this is indicative of the ways the policy needs to be reformulated (Ham & Hill, 1984; Sabatier, 1986).

Conversely, the bottom-up approach to the policy cycle considers policy formulation and implementation as indiscrete processes where policy goes through reformulation stages as it is being implemented. Analysis at different stages, therefore, is not beneficial to understanding the reasons for a success or failure of a policy. This approach advocates that it is more beneficial to see the whole formulation/implementation of a policy as one stage. This instead involves identifying the key players involved in the policy process and their interrelated relationships as they relate to the policy (Ham & Hill, 1984; Sabatier, 1986).

The similarity between these two approaches is that they both seek to understand to what extent policy has achieved its desired outcome (Spicker, 2006). Or as Sabatier, one of the earliest writers on policy implementation, claims in less technical terms, ‘to what extent a policy is effective at doing its job’ (1986).

There are many arguments about which method is the most valuable. There is much documentation of this discussion contextualised by different disciplines of study. Evan et al. (2004) write in their paper about using both a top-down and bottom-up approach to better understand indicators for environmental sustainability. Three points were obvious in the process: firstly, a bottom-up approach to policy making empowers the community who help make the decisions. Secondly, a bottom-up approach to policy making has to have stakeholder consultation as part of the process, or both the stakeholders and the policy makers will disregard it. And thirdly, as political and ecological boundaries are often incongruent, a partnership of top-down, formal, political knowledge and bottom-up, local, specialised knowledge is needed as these boundaries may not be obvious (Evan et al., 2004).

Meredith Honig, highlights in her (2004) article “Where’s the ‘Up’ in Bottom-Up Reform?” that a bottom-up approach to educational policy analysis is often marred when researchers and practitioners take an implementation focus of policy in schools as opposed to an exploration of the roles that policy makers play in this process, which could potentially endorse beneficial changes in schools.

It seems that both these approaches have merits and downfalls as illustrated by the arguments summarised above. The factor that determines which method is deployed in the analysis of policy is dependent on the focus one hopes to gain insight into. That can be either an outcomes based focus in the case of a top-down analysis or a process based focus in the case of a bottom-up analysis. A top-down approach has an outputs based focus which denotes that a policy needs to reach its target regardless of the process it takes to get there, and the bottom-up approach focuses on the whole process, which includes the complex interactions between policy players and stakeholders (Sabatier, 1986).

The following section will analyse New Zealand’s HIA policy in a quantitative, top-down manner based on the inclusion of disability awareness in the performed HIA cases from England, Scotland, Australia and New Zealand. The top-down method is the best suited technique to understand how effective the implementation of the HIA policy is in catering for people with disabilities. This analysis aims to understand to what extent the HIA policy has reached its target population as demonstrated by the inclusion of disability (Spicker, 2006). This can be seen through analysis of the HIA case reports from completed HIA assessments.

As the percentage of people who experience disability in New Zealand society is quite significant (20 percent) (ODI, 2001), and the guiding HIA policy has a relatively high awareness of people with disabilities (as explained in the previous chapter), it would be presumed that people with disabilities would be considered in almost all New Zealand HIA assessments that are performed.

5.3 DISABILITY INCLUSION IN HIA CASE STUDY INVESTIGATION

The tables and graphs below show the outcomes of the disability inclusion results for the reviewed completed HIA case studies from England, Scotland, Australia and New Zealand.

The most frequent classification score has been highlighted in the table. Following this, the data has been presented as a bar graph. This has been done as the sample sizes from each country were variable. Therefore the absolute results of each category between each country are not comparable. These results are clearer to understand as bar graphs. As explained in the methodology chapter, the classifications are as follows:

CASE STUDY DISABILITY INCLUSION CATEGORIES

- 0- Contains no disability inclusion within the case study.
- 1- Contains inclusion of disability only in HIA theory.
- 2- Contains inclusion of disability only in theory and screening stage of HIA.
- 3- Contains inclusion of disability only in theory, screening and scoping stage of HIA.
- 4- Contains inclusion of disability to a level 3 and also translates scoping into recommendations to cater for disability in a non specific way.
- 5- Contains inclusion of disability to a level 4 and also translates scoping into recommendations specific to disability.

Table 5.1: Scotland

Score	Frequency	Percentage of total (% tp 1 d.p)
0	2	16.6
1	0	0
2	1	8.3
3	1	8.3
4	1	8.3
5	7	58.3
Total:	12	100

Table 5.1 shows that the assessed Scottish HIA cases demonstrate the highest disability inclusion out of the countries that have been studied. However due to the small sample size of examples analysed, there may be a significant margin of error.

From the Scottish disability inclusion table it can be seen that a large majority of the case studies fall into a level 5 category. For example, the Minerals Local Development Plan (Scotland, 2010) explicitly talks about the effects of mineral extraction on people with disabilities including air

quality and traffic. This means that a majority of the case studies contain inclusion of disability in theory, screening, scoping and general recommendations and also translate scoping into recommendations specific to disability. This demonstrates that we can say with some certainty that the practitioners of these HIA cases have been consciously thinking about people with disability when performing the HIA. Though the Scottish HIA guidelines do not show a high inclusion of disability awareness in their guiding procedures, the political ideology that Scotland was under when most of these HIAs were performed, as well as the impact of the Disability Rights Movement would have put disability awareness and equity high on the priority list. This is similar to other Scottish social policy in this time (The National Archives Legislation, n/d). The scores of the Scottish HIA cases are evenly spread except for slightly more case studies having no disability awareness in them, and more than half exhibiting a level 5 inclusion.

The results of this analysis cannot be explained by the disability awareness in the guiding HIA rhetoric.

Table 5.2: England

Score	Frequency	Percentage of total (% tp 1 d.p)
0	6	6.7
1	4	4.5
2	1	1.1
3	15	16.9
4	25	28.1
5	38	42.7
Total:	89	100

Table 5.2 shows a very similar awareness of people with disabilities to table 5.1. England, like Scotland, demonstrates a very high awareness of disability issues in the performed HIAs. This is the second highest of the countries involved in this analysis, with a large majority of cases being classified in the top two categories. From the English disability inclusion table it can be seen that a majority of the examples fall into a level 5 category. This means that a majority of the cases contain inclusion of disability in theory, screening, scoping and general recommendations and also translates scoping into recommendations specific to disability. This allows us to infer that it is highly likely that the practitioners of these HIA cases have been consciously thinking about people with disability when performing the HIA. The HIA reports that showed a category ‘5’

inclusion of disability is less frequent than that of Scotland. However, it must be noted that the number of HIA reports in category '0' are fewer than of Scotland, indicating that the general acknowledgement of disability inclusion is higher in England than it is in Scotland. Some of the English HIA examples which showed a thorough awareness of disability in HIA procedures include the 2014 Commonwealth Games Health Impact Assessment Report. This discusses disability extensively and considers it in every part of the games, including access and special concessions, although there is little evidence in scoping stage. This could be expected as though English policy guidelines do not have a high inclusion of disability awareness in them, the political ideology that Britain was under when most of these HIAs were performed and the impact of the Disability Rights Movement may have endorsed disability awareness and equity as a priority in HIA.

Due to the high scores in category 5 and therefore the demonstration of a high disability awareness, it could be assumed that the guiding HIA rhetoric would mirror this. However, this assumption has been disproved by the findings presented in chapter four, table 4.1.

Table 3: Australia

Score	Frequency	Percentage of total (% tp 1 d.p)
0	5	31.3
1	0	0
2	0	0
3	2	12.5
4	2	12.5
5	7	43.8
Total:	16	100

The assessed Australian HIA cases show the third highest awareness of disability issues of the countries involved in this analysis. However, due to the small sample size of the examples studied there may be a significant margin of error.

A varied awareness of disability is demonstrated by the high frequency in both the 0 and 5 categories. The trajectory shows an increase in the 3 and 4 categories, indicating that some disability awareness has been taken into account and quite a substantial increase in the 5 category indicating that specific disability recommendations have been thought about. Though Australia

demonstrates a higher level 5 score than that of England, it also shows a higher level 0 score than England, indicating that people with disabilities have not been identified in even the screening process.

This unanticipated pattern could be partly due to the political ideology of the government in power when these HIAs were performed with a conservative approach to the Third Way. This could also be because of the lack of disability awareness in the Australian HIA guidelines. The results of this analysis can only be partly explained by the disability awareness in the guiding HIA rhetoric.

Table 4: New Zealand

Score	Frequency	Percentage of total (% tp 1 d.p)
0	3	16.7
1	1	5.6
2	0	0
3	3	16.7
4	4	22.2
5	7	38.9
Total:	18	100

Assessed New Zealand HIA case studies show the lowest awareness of disability issues in performed case studies of the countries involved in this analysis. The New Zealand disability awareness scores are largely homogeneous showing a small but steady increase in disability awareness in the categories 3, 4, and 5. However, level 0 is an over-represented aberration that does not fit into this steady incline. This over representation also decreased the impact of the increase in the level 5 ‘specific disability recommendations’ category. Though level 5 was the majority of all the categories, this was expected to be higher due to the government ideology at the time which would have had a high emphasis placed on equity and disability awareness. This was also the reason that the New Zealand trajectory of the awareness of disability issues in HIA, which is similar to that of the Australian analysis, was expected to be higher.

As the New Zealand HIA guidelines give the most comprehensive coverage of people with disability of all the countries investigated, New Zealand would have been expected to show the

highest scores of disability awareness in performed HIA reports of all the countries. The results of this analysis can only be partly explained by the disability awareness in the guiding HIA rhetoric.

5.4 SUMMARY

This chapter has defined the methods used to analyse policy and then illustrated the way in which a top-down analysis of HIA policy has revealed that the practice of disability assessment in performed HIA differs in different countries around the world.

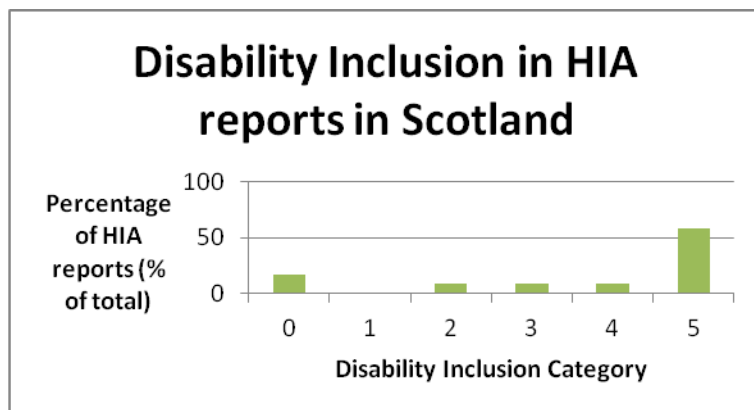


Fig 5.1: Scotland shows the highest disability inclusion in its performed HIA cases out of the countries that have been studied. This is despite being one of the countries with the lowest awareness of disability in its HIA guiding rhetoric.

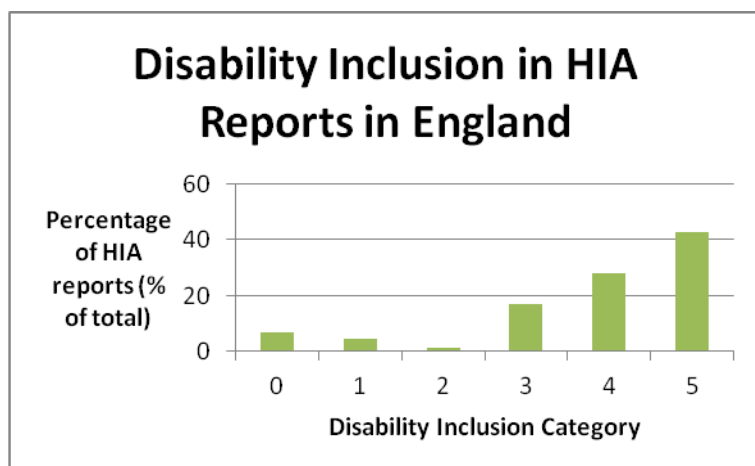


Fig 5.2: England shows the second highest disability inclusion in its performed HIA case studies out of the countries that have been studied, despite being one of the countries with the lowest awareness of disability in its HIA guiding rhetoric.

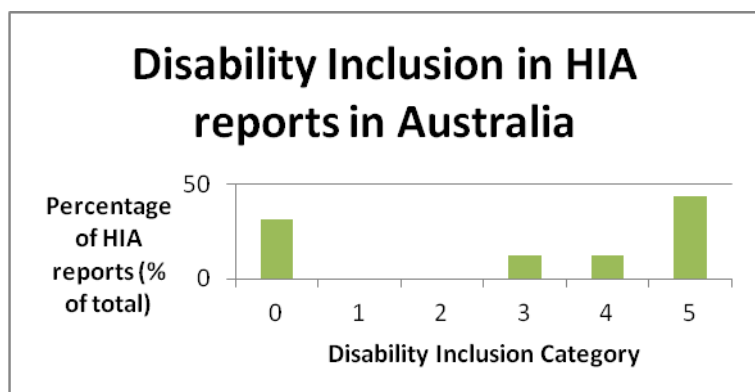


Fig 5.3: Australia shows the third highest level of disability inclusion in its performed HIA cases out of the countries that have been studied despite illustrating only partial awareness of disability in its HIA guiding rhetoric.

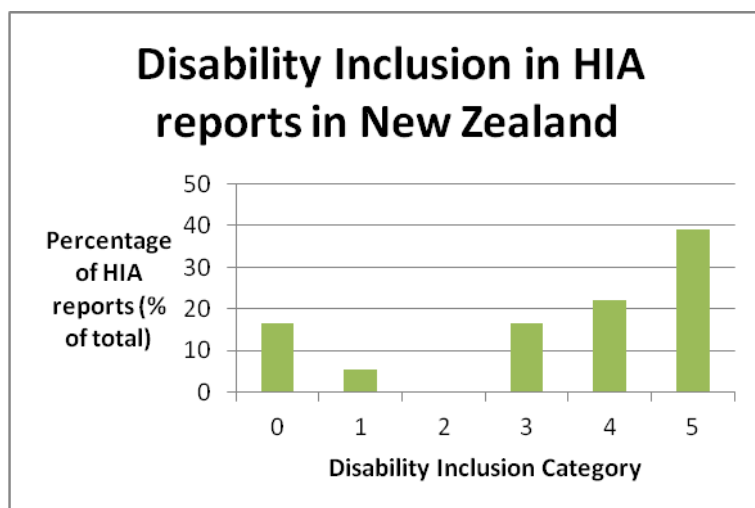


Fig 5.4: New Zealand shows the lowest disability inclusion in its performed HIA cases of all the countries studied, despite having the highest disability awareness in its guiding HIA rhetoric. As this policy specifically aims to recognise all disadvantaged populations in a society, this result is an unanticipated outcome.

On the basis of the above table 5.4 and its accompanying explanation, it appears that the guiding procedures for HIA in New Zealand have not had as significant an effect on the practice of disability awareness in HIA as would have been expected. It would seem that the policy has only been partially successful in meeting its goals of endorsing equity in the form of disability awareness in HIA practice. Other factors such as the Disability Rights Movement, the political government and ideology of the country at the time the assessed HIA reports were completed (as explored in the previous chapter), seem to be more indicative of the level to which the awareness of disability issues is incorporated into HIA. There could be many reasons for the observed discrepancy between the disability awareness in HIA policy and practice in New Zealand, some which have been defined in the literature I will discuss in the following chapter.

In the following chapters, to verify any of the arguments presented in this literature as they relate to HIA in New Zealand, I will report on a bottom-up analysis of the HIA policy. This will involve interviews I have undergone with key actors involved in the production of the New Zealand HIA policy guidelines and those involved in the HIA practice. It is assumed that the combination of these people will have the best ability to give me further insight into the discrepancies that I have seen in this research involving disability inclusion in policy and practice in the HIA in New Zealand.

CHAPTER 6: TOWARDS A THEORETICALLY INFORMED UNDERSTANDING OF THE GAP BETWEEN POLICY AND PRACTICE

6.1 INTRODUCTION

This chapter discusses the literature which contributes to our understanding of the relationship between policy and practice. The literature suggests that although policy rhetoric may be ambitious, this is not always translated into practice.

The literature explaining this apparent ‘gap’ in the application of HIA as a policy tool in relation to the needs of people with disabilities can be broken up into three broad categories. These are: generic barriers to HIA; barriers specific to the enactment of policy in the disability sector; and ‘feminist interpretations of the construction of disability’, which could potentially explain the policy/practice gap. These three categories will be reviewed in this chapter and will inform the analysis of the interviews in the following chapter.

CHAPTER OVERVIEW:

- Section 6.2 presents general literature on why policy is not invariably translated into practice.
- Section 6.3 provides an overview of literature that could potentially explain why HIA policy is not always translated into practice in the disability sector.
 - Section 6.3.1: literature on unconscious attitudinal barriers faced by people with disability which may figure as policy barriers.
 - Section 6.3.2: reviews literature on generic limitations to HIA policies.
 - Section 6.3.3: literature on the ‘feminist interpretations of the construction of disability’, which could also potentially explain the policy and practice gap in HIA in New Zealand, as revealed in the empirical findings in earlier chapters.
- Section 6.4 summarises the findings of the chapter in order to investigate in the following chapter (chapter seven) why disability awareness in HIA policy in New Zealand is not always translated into practice.

In their book *Studying Public Policy*, Howlett and Ramesh (1995) make the statement that ‘translating programs into practice is not as simple as it may appear’ (p.154). They attribute the reasons that a program may not work to ‘the nature of the problems, the circumstances surrounding them or the administrative machinery in charge of the task’ (Howlett & Ramesh, 1995, p.154).

Firstly, the nature of the problems is a reason that the implementation of policies designed to address them may not work. The authors use the example of closing a casino as opposed to eliminating gambling as an example of this point. The former will cause contention, but only at a local scale, and is therefore more straightforward, whereas the policies to address the latter are hugely multi-faceted and will cause contention at a larger scale level, hence the policy may not be able to be effectively implemented (Howlett & Ramesh, 1995, p.155).

Secondly, the ‘circumstances surrounding the problem’ are a reason that the implementation of policies designed to address the problems may not work. For example, problems like domestic violence occur due to a myriad of reasons, and therefore the policies designed to address this are unlikely to address the problem in its entirety (Howlett & Ramesh, 1995, p.155).

Thirdly, the ‘administrative machinery in charge of the task’ may be a reason that the implementation of policies designed to address certain tasks may not work. The larger and more diverse the group of policy actors and stakeholders surrounding a policy, the less likely it is for that group to come to a strong consensus regarding the policy implementation. Hence it is harder for the policy to reach its potential outcomes (Howlett & Ramesh, 1995).

Robert Gregory (2009), in his paper “Public policy, saying one thing and doing another”, talks about the ways that policy is often not translated into practice and attributes this to public policy formulation being a process that is dictated primarily by political motivations as opposed to technical rationality, which in his view is how policy should be ideally made. He explains that in liberal democracies, political power is often disguised behind technocratic methods which appear to have no biases (Gregory, 2009). For instance, the medical model of disability is perceived to be ‘technically rational’ by the professionals who define it. However, attitudinal and political reasons have been a major factor in its formation. The very term ‘rational’ is a socially defined concept, and therefore it is impossible for it to be void of human values. Loxley and Thomas (1997) agree with Robert Gregory’s explanations of the factors that impair the translation of

policy to practice, and further define the ‘political power’ that impairs the translation of policy to practice as being a process where the power of professionals is only a function of the non-participation of society (Loxley & Thomas, 1997).

Similarly, when professionals understand the ways that people with disabilities are only disabled by the society they live in, as defined by the social model of disability, the paternalistic role they formerly had within the medical model means that the professional is taken out of the dominant position in the policy formulation process. The onus is then placed instead on the person with the disability to have a part in the formation of policies. It is therefore not in the professional’s best interests to implement policies that are written according to the social model of disability. There are conflicts between policy written from a person-centered, social model perspective and attempts to understand ‘disability’ from a holistic viewpoint. This is opposed to the medical model which takes a more problem-centered approach and tries to attend to disability from that perspective.

6.2 WHY DISABILITY AWARENESS IN HIA POLICY IS NOT ALWAYS TRANSLATED INTO HIA PRACTICE

Literature that could potentially explain the reasons why policy is not always translated into practice in the field of disability falls into three main schools of thought. Firstly, there is generic barriers to HIA literature which could be applied to disability issues; secondly, there is specific disability literature of policies which have not been translated into practice; and thirdly there is literature that accounts for the ‘feminist interpretations of the construction of disability’, which could explain why people with disability are undervalued and marginalised in the policy practice process.

6.2.1 UNCONSCIOUS ATTITUDINAL BARRIERS FACED BY PEOPLE WITH DISABILITIES

This literature focuses on value-based perceptions specific to people with disabilities. This literature is part of the social model of disability literature discussed earlier (in section 2.3.2). Some of these reasons include not recognising people with disabilities as a disadvantaged group, or not recognising them as a population in their own right, or not being aware of the issues they face unless someone points them out. In the context of HIA practices, this bias may be reflected in value-based judgments of how important as a group people with disabilities are in the HIA

process. This can also be reflected in the models or attitudes that underpin peoples' understandings of disability; the problem-centred medical model, or the person-centred social model. Below are examples of overseas policy contexts illustrating different understandings of the attitudes that professionals and others have towards people with disabilities.

In Scotland, it has been pointed out that there is often a gap between theoretical planning and practical implementation of discharge policies for people with disabilities from institutions (Parlais, 2009). Varying conceptualisations of deinstitutionalisation are a barrier to the implementation of discharge policies. Specifically, the range of ideas held by each professional – psychologists, psychiatrists, social workers, and nurses – involved in the discharge process differ. These different conceptualisations of disability, embedded in the social vs. medical model understandings are a barrier to the implementation of the policies (Parlais, 2009). An important prerequisite for a successful policy is that all those involved should have a common understanding as to the theoretical underpinning of the policy.

From Lithuania, Dainus Puras (2009) writes that one of the barriers to translating research policies into practice for children with learning disabilities is that there is often little communication between politicians, professionals, and the children's parents. It is also important that politicians understand the social model when designing their policies; placing the onus of a disability on the child and their family as opposed to the environment around the child is not a progressive approach as defined by the social model of disability and does not help children with disabilities.

In the United Kingdom, the *Disability Discrimination Act* requires health services to remove barriers of access and participation to health services (Carter & Markham, 2001). However, discrimination exists within the health system due to failure to understand the implications of the social model of disability which places the responsibility of dealing with the disability squarely on society. For example, this occurs by not providing people with accessible formats to literature such as enlarged print or Braille (Carter & Markham, 2001).

Irish learning disability policy fails to acknowledge that services need to be person-centred rather than being economically-centred. For example, long-term housing for people with severe learning disabilities is often provided significant distances from their communities and supports. This is due to the 'high-cost, low-value' perception of provision of this accommodation. However, if people were at the centre of the policy being made, there would be more

accommodation in more localities, better suited to more disabled people (Mansell, 2008). These are the sorts of concerns a disability-friendly HIA would be expected to identify.

Canadian disability policy academics Jongbloed and Crichton (1990) write that some of the reasons that socio-political policies regarding people with disabilities are not successful in reducing the barriers that people face is because of the failure to accept the progressive models, such as the social model of disability, which can be used to cater for those with disabilities. This is especially true of income and employment policies in Canada, which pose major barriers to people with disabilities.

Hence, the above selection of international examples show that discrepancy between HIA policy and HIA practice could be due to the understandings that those carrying out the HIA hold as to what the social model of disability means, and the potential importance of its application in the HIA context. This may cause a misunderstanding as to whether disability belongs to the individual (as the problem-centred medical model defines), or whether it is a responsibility of society (as the person-centred social model explains) and thus can be catered for by societal policies.

6.2.2 *GENERIC HIA BARRIERS*

There is a significant body of literature highlighting barriers to the implementation of the HIA tool, which could apply to any HIA. A full summary of generic barriers to HIA which may limit disability awareness in HIA can be found in the literature review (section 2.4). Some of the most pertinent reasons that may limit the practice of disability policy in the HIA are: narrow political agendas, which lead to a failure of government support and commitment; attitudinal barriers such as a misunderstanding of the HIA model and its benefit to long term health outcomes; and the value it has as a policy tool. This conflict of perceived ‘value’ will dictate the commitment given to HIA. Barriers such as a lack of resources (which constitute time, funding and staff), are cited by Signal, Langford and Quigley (2006).

6.2.3 *FEMINIST INTERPRETATIONS OF THE CONSTRUCTION OF DISABILITY*

Feminist understandings of disability can provide a deeper understanding as to why people with disabilities are not fully acknowledged in HIA practice.

Feminist literature takes a view that can enrich disability studies rhetoric (Garland-Thomson, 2002). This is because many of the issues that help to explain the historical (and sometimes contemporary) demoralising treatment women in some societies endured due to the acts of their male counterparts can be likened to the way that people with disabilities are treated in society today (Morris, 1993; Rohrer, 2005). It is an issue that has been 'hidden and disregarded for too long' (Rohrer, 2005, p. 1).

This critique is largely based on the concept of 'othering'. 'Othering' is a concept which comes out of dualism that explains that males see themselves as 'the norm' and view women in relation to themselves as being in deficit, otherwise described as being 'the other'. Plumwood (1993) explains the dualistic tendency of Western thought. Edward Said talks about 'othering' in context of imperialism. The creation of the 'other' is done by highlighting their weakness, thus extenuating the moral responsibility of the stronger self to educate, convert, or civilize depending on the identity of the 'other'. Indeed, as defined by Martin Jones et al., 'othering' is a 'term, advocated by Edward Said, which refers to the act of emphasizing the perceived weaknesses of marginalized groups as a way of stressing the alleged strength of those in positions of power' (Said, 1979, xviii). 'Othering' can be done with any racial, ethnic, religious, or geographically-defined category of people. Nancy Jay (1981) in her paper "Gender and Dichotomy" explains that dualistic definitions of the 'norm' are constructed while the 'other' is outside the circle. Women are seen as 'deformed men', and so are devalued and not entitled to the same rights (Wendell, 1989; Garland-Thomson, 2002).

Similarly, people with disability who may look different to the 'norm' are seen as the 'other' and are therefore not privy to the same perceived values and equal rights as their able-bodied counterparts (Wendell, 1989; Garland-Thomson, 2002; Adkins 2003). Adkins also explains the way that the concept of 'othering' prevents people with disabilities being thought of as part of society. This may mean that when policy is being formed and implemented people with disability are not thought of as an important part of the formulation of the policy process.

Michel Foucault's writings are also very pertinent to the concept of otherness. Foucault writes that the underlying reason some people are seen as the 'other' is as an exercise of 'power and dominance' over a subordinate group (Adkins, 2003). Devaluing the identity of those with disabilities justifies the feelings of power and dominance. When people with disabilities are seen as peripheral (or 'other'), they then define the norm (Adkins, 2003). Adkins uses Foucauldian

theory to explain that able-bodied people see people with disabilities as ‘helpless victims’, who are in need of ‘support’ (p. 12). This rationalises the need for a new profession to control and scrutinize people with disabilities (Adkins, 2003). This may have implications for the practice of policy by those in power.

Adkins, using Foucault’s writings in *The History of Sexuality Vol. 1: The Will to Knowledge* (1984), explains that sexual offenders are seen as ‘deviant’ as they perform acts which are seen as largely to defy normal human values. This action is seen not only as a violation of normal human conduct, but also reflects upon the individual who is also seen as exhibiting behaviours which are deemed as not the ‘norm’ and hence inferior. Adkins explains: ‘This justifies scrutiny, coercion, and exclusion’ (2003, p. 23). Adkins describes how people with disabilities are treated as ‘deviant’ due to the behaviours they exhibit which may be outside the ‘norm’ and this explains why people with disabilities are marginalised in society and labelled with a ‘deviant’ status (Adkins, 2003, p. 26). Such an understanding by able-bodied HIA policy practitioners of people with disabilities may rationalise the failure to consider people with disabilities in HIA reports. As people with disabilities may exhibit behaviours and appearances dissimilar to the ‘norm’, HIA practitioners may not see them as fully part of society, and may therefore exhibit a cognitive blindness to their needs.

Val Plumwood, in her 1993 book *Feminism and the Mastery of Nature*, makes a distinction between the dualistic relationship of ‘master’ and the ‘other’. She presents five mechanisms for creating ‘otherness’:

1. Denial – based on a denial of dependence that the master has on the ‘other’. If not dependent on them for services, he or she is dependent on them for the construction of their identity. The ‘other’ is constructed as inessential, unimportant or peripheral, in spite of their objective importance (p. 48). People with disabilities may endorse the construction of able-bodied society, and be seen as marginal in the HIA process.
2. Radical exclusion or hyper-separation – the ‘other’ is described in a way that makes him or her seem to be radically different from the master, with no overlaps in characteristics or status. This rationalises his ignorance of the ‘other’ (p. 49). The appearance and behaviours of people with disabilities may be deemed as ‘so far out of the norm’ that they are not acknowledged as a part of society.

3. Relational definition – is a process which means the master defines the existence of the ‘other’ only in relation to himself. Generally, the ‘other’ is seen as being in deficit in relation to the master, who is defined as the norm (p. 52). People with disabilities are only ‘disabled’ when comparing them to the ‘norm’. This is because when comparing them to the norm they are perceived to lack abilities.
4. Instrumentalisation – involves the perceived needs and goals of the ‘other’ being defined by the master and in relation to what the master wants. The ‘other’ is not seen as having important independent goals or desires (p. 53). When this mechanism is operating, it will be quite subtle in its effects, and probably be working unconsciously.
5. Homogeneity – people defined as ‘other’ are seen as being like each other in most ways. They are stereotyped and placed in broad categories. For example, ‘women and children’ are seen as one category, in spite of the fact that they are very different from each other (p. 53). Similarly, disabled people are often lumped together with the elderly, in spite of the manifest differences between these groups.

Wendell (1989) underwent an illness leaving her with a ‘disabling chronic, disease’ (p. 1). She writes of the ways that able-bodied people did not understand the issues that affected her most. She believes that this is not a reason for these able-bodied people to plead ignorance when it comes to essential disability provision.

Goggin and Newell (2005) place Wendell’s comment into a policy context stating that the reason there is so much policy that has a negative impact on people with disabilities is because the policies are being made by able-bodied people who do not understand the issues that people with disabilities face. Their answer to achieving better outcomes for policies designed to aid people with disabilities is to employ more people with disabilities in influential roles in government (Goggin & Newell 2005).

6.3 SUMMARY

There are many reasons in the literature that could potentially explain the discrepancy between the disability awareness exhibited by HIA policy and practice. These reasons could be due to generic barriers to HIA, or they could relate to attitudinal barriers to people with disabilities; as explained by the social model of disability. Or, more fundamentally, they could be a consequence

of the devaluation of people with disability, as explained in the ‘feminist interpretations of the constructions of disability’ literature.

All three of these bodies of literature are potentially valuable to explain the barriers applying to disability acknowledgment in HIA procedures in New Zealand. In the following chapter, based on in-depth interviews with HIA actors who have experiential insights into New Zealand HIA procedures, I will draw on the literature reviewed above to explain the policy implementation gap in relation to the HIA procedures’ acknowledgement of people with disability.

CHAPTER 7: AN EMPIRICALLY INFORMED ANALYSIS OF THE REASONS FOR THE POLICY-IMPLEMENTATION GAP IN HEALTH IMPACT ASSESSMENT IN NEW ZEALAND

7.1 INTRODUCTION

There are many ideas presented in the literature that could potentially explain reasons why disability policy is not invariably translated into practice, as exhibited in the previous chapters (four and five). Informed by this review, this chapter presents analysis of interviews with key actors involved in the HIA process. Three of these informants were HIA policy makers, and three were HIA policy practitioners. The objective of these interviews was to gain an insight into the reasons why disability policy is not always translated into practice in the HIA in New Zealand.

CHAPTER OVERVIEW:

Sections 7.2 to 7.6 will present a summary of the conversations with each respective interviewee, as I interpreted them. The reporting sequence is as follows:

- Section 7.2 Interviewee A
- Section 7.3 Interviewee B
- Section 7.4 Interviewee C
- Section 7.5 Interviewee D
- Section 7.6 Interviewee E

These summaries provide a broad context of the interviewees' understandings as they relate to HIA and disability. The interview narratives are included in Appendices F, G, H, I and J.

- Section 7.7 presents a thematic analysis of the ideas extrapolated from the narratives, highlighting the barriers to recognition of people with disabilities in the HIA process. The 'feminist interpretations of the construction of disability' barriers discussed earlier in the literature review did not emerge in the thematic analysis of interviews. Hence, in

- Sections 7.8 and Section 7.9, the ‘attitudinal’ and ‘generic’ barriers presented in table 7.1 are reassessed from a ‘feminist interpretation of the construction of disability’ perspective to reveal the potential deep-seated barriers to effective inclusion of people with disabilities in HIA. Although these reasons were not explicitly revealed in the interviews (as they are likely to be largely unconscious), I found this a useful explanatory theory to apply to underpin the reasons expressed in the interviews.

7.2 INTERVIEWEE A

Interviewee A is an HIA practitioner and works for a private consultancy in Auckland.

Though Interviewee A has performed a disability assessment in almost all the HIA cases he has worked on, he is the first to admit that these assessments could have been done better. He feels that the ways the disability assessments have been carried out have not been appropriate for the population they are trying to reach. He feels that the methods that have been used to recruit people with disabilities to be involved in the scoping meetings have not been proactive, or appropriate. He considers the format of information that is given to those in the scoping meetings is not always appropriate and he also acknowledges the differing needs of this population. He understands that the benefits of holding a one-on-one meeting would be more valuable than having disabled representatives as part of the general scoping meeting. The two reasons he alludes to in his explanation of this oversight are a lack of funding by the Ministry of Health (MOH), and a cognitive blindness of those who facilitate the project. He feels that when the HIA practitioners are trained there is little information given to them on how to communicate with disadvantaged populations and he does not remember people with disabilities constituting an example of a disadvantaged population within the training program.⁶

7.3 INTERVIEWEE B

⁶A full narrative of this interview can be found in Appendix F.

Interviewee B was the project team leader for the PHAC in 2005 at the time the present HIA guidelines were written. She was handed the HIA folder by her predecessor.

Interviewee B has been involved in the production of the HIA guidelines. She feels that disability has been acknowledged in these guidelines, and the reason that this policy is not practised could be due to any of the three bodies of literature researched. She feels that people with disabilities are not cognitively thought about in the HIA process. Even if those working on the HIA have experienced working with people with disability, she feels that HIA practitioners do not necessarily understand the social model of disability, and she also feels that many generic barriers (such as funding and government mandate) limit the scope of an HIA. She also adds that another reason for the poor recognition of people with disabilities in the HIA process could be due to the training of the HIA practitioners which does not comprehensively make them aware of people with disabilities. However, when recommendations are made which could apply to people with disabilities, they often aim to cater for this population.⁷

7.4 INTERVIEWEE C

Interviewee C is a consultant who was integral to the production of the 2005 HIA guidelines and presently works as a practitioner in the HIA field. For this reason his responses have both an HIA practitioner and a policymaker slant.

Interviewee C comes from a political activist background. He has known people with disabilities, and his experience of them is considerable. He feels that personal experience and training are the main factors that determine what HIA practitioners do and do not think about in HIA practice. However, he still feels that his own experience does not influence him enough to think about people with disability as a group who need specific assessment, and recommendations in HIA practice. He feels that as there is no mandatory requirement or legislation dictated by the government to consider people with disability in the HIA process (or any other process), as people of Māori ethnicity are, people do not bother. He feels that the prioritisation process has more or less been set before it happens, and people with disability are not part of the outcome.

⁷A full narrative of this interview can be found in Appendix G.

He feels that government priorities are more important in this process. He also feels that the government take-up of this tool has been less than desirable and therefore government funding has also limited the scope of HIA; which may include neglect of people with disabilities. When people with disabilities are acknowledged in an HIA, they are not often acknowledged as a specific group, but rather as a proxy along with old people.⁸

7.5 INTERVIEWEE D

Interviewee D was in the secretariat to the Public Health Advisory Committee (PHAC) in 2005 when the present HIA Guidelines were written, and played an important role in their production.

Interviewee D feels that the understanding of the concepts endorsed by the HIA are not well understood, and feels the reasons why people with disability are sometimes not well assessed in HIA practice is due to the poor methodologies of HIA practitioners in the scoping process. This in turn is influenced by the limitations of resources allocated to the HIA; mainly time and funding. She also thinks that attitudinal barriers towards people with disabilities are an important factor as to why disability may not be fully assessed, which needs to be addressed by an increase in social awareness. She feels training of HIA practitioners and consciousness-raising around people with disabilities is a pertinent issue in ensuring that disability is considered in the HIA process. She also indicated that government may sometimes override priorities that are indicated by the community.

She was unsure of the reasons why disability was often neglected in social policy. It is possible that she was not willing to admit that it was something she had never questioned before (Yanos & Hopper, 2008).⁹

7.6 INTERVIEWEE E

Interviewee E is an HIA practitioner who works for a private consultancy and is commissioned to undertake HIAs in New Zealand.

⁸A full narrative of this interview can be found in Appendix H.

⁹A full narrative of this interview can be found in Appendix I.

Interviewee E does not feel that people with disabilities are an exclusive group. He argues that disability is spread across all sectors of society; hence, they do not need attention as an exclusive group in HIA practice. He cites his friend's experience who uses a concrete ramp to access the harbour to go swimming. This may indicate that Interviewee E is not aware that all people with disability may not have the same confidence and outgoing nature that his friend has in accessing recreational facilities, and may need more aids. This may indicate that Interviewee E feels that people with disabilities will and should have the confidence to work with whatever is provided, which may also mean that he feels the HIA does not have a responsibility to provide for this population. Interviewee E also cites that he is not responsible for the groups that get scoped in the HIA process, and the onus is on the community in the room. However, he goes on to point out that he 'would like to think that he can' direct the thinking. So, the question is whether he would direct the discussion towards disability if this sector is not represented in the scoping meetings. Contrary to other interviewees' responses, Interviewee E thinks that the training he delivers to potential HIA practitioners in New Zealand uses people with disabilities as an example similar to any other group.¹⁰

7.7 ANALYSIS OF INTERVIEW FINDINGS

Based on a thematic analysis of the interview data, Table 7.1 below lists the key themes identified in the interviews. These have been divided into two categories of 'attitudinal barriers to people with disabilities' and 'generic HIA barriers', as discussed below in this section.

The analysis of the barriers is extended in the next two sections (sections 7.8 and 7.9) by re-examining the thematic barriers through the lenses of feminist theory. In this way, it can be seen that the barriers to recognition of disability in HIA constitute three levels:

- The specific attitudinal barriers to people with disabilities;
- The generic barriers to HIA; and
- The feminist interpretations of the creation of disability barriers

¹⁰A full narrative of this interview can be found in Appendix J.

Table 7.1 Analysis of barriers to recognition of people with disability in HIA in New Zealand

Attitudinal Barriers to People with Disabilities

1. UNDERSTANDING OF DISABILITY

A. By HIA practitioners:

- The practitioner's understanding of the social model would shape their attitude and approach to according recognition to people with disabilities in HIA.

B. By Community

- Poor understanding by the community of the social model view of disability

2. ADVOCACY

A. Community Advocacy

- There are few community voices promoting disability in HIA.

B. HIA Practitioners Advocacy

- Without advocacy for people with disabilities, they are often neglected in HIA practice.
- Cognitively HIA practitioners forget about people with disability unless they are a focus of the HIA
- The community awareness of people with disabilities is variable and therefore they are not always thought about.
- People with disabilities are often not defined as a distinct group, but rather lumped together with other groups who face similar barriers, such as old people and mothers with prams.

C. Self Advocacy

- People with disability do not have a unified voice or strong political presence.
- People with disabilities are not represented at every workshop. They need to be specifically recruited as forum members as they are the ones who can prioritise
- People with disability need to be involved and advocate for themselves.

D. Government Advocacy

- Disability does not really belong in the medical or social side of the government; it falls between the cracks and gets marginalised.
- New Zealand has a legislative duty to prioritise Māori, Pacifica and low income people and children are also deemed as important and disability is often left off the list of those that need to be scoped.
- People with disability do not have a very big voice and there is often a lot of competition for voices to be heard.
- Unless there is some legislative mandate, people with disability will not be on the public policy agendas, including the HIA agenda.

3. INAPPROPRIATE CONSULTATION

- The format of information at the HIA workshops needs to be specific for the needs of the people with disabilities.
- Often, the practitioners do not think about people with disabilities having specific needs the way the Māori do.
- No specific disability HIA workshops have ever been held. More could be done to involve people with disabilities in HIA.

Generic Barriers to HIA Practice

1. TRAINING/ GUIDANCE/ EXPERIENCE OF HIA PRACTITIONERS

- Training and guidance may influence the understanding of the social model by a practitioner.
- Dependant on the expertise of who is doing the HIA and whether disability is something they know about.
- The practitioner's personal passions influence the way they conduct their HIA practice.

2. CANNOT ADVOCATE FOR ONE GROUP TOO STRONGLY

- When providing training, one group cannot be advocated too strongly as it becomes boring to other trainees.

3. DECISIONS AROUND WHO GETS SCOPED

A. Funders

- Those who commission the HIA are the ones who have the final say of what goes in the HIA, what the focus is on and who gets scoped.

B. HIA Practitioners

- The priority populations that are assessed are pretty much decided before the actual scoping takes place. Disability groups are not considered as one of those priority groups.

C. Scoping Community

- Depends on who is in the scoping room as the community sets the agenda of the groups that need to be scoped.
- Depends on what the issue is and the big concerns in the community are at the time as to what the stakeholders prioritise.
- As HIA requires feedback from the community about different groups in reaction to different health determinants, there is a large amount of information communicated.

4. RESOURCE PRESSURES

- Lack of resources (time/ money) prevents all groups being thought about.
 - Funding pressures mean that all groups cannot be assessed according to the format that is most appropriate for them.

5. AWARENESS OF MINORITY POPULATIONS

- Minority groups are left out until there is a specific formal procedural requirement such as the Whānau Ora tool.

As shown in the table above, the attitudinal barriers to people with disabilities fell into these three categories: understanding of disability by HIA practitioners and community, advocacy by community, by HIA practitioners, by government and self-advocacy by people with disabilities themselves, and finally, inappropriate consultation. These identified barriers were accompanied by generic barriers to disability awareness in HIA practice, which included training/guidance/experience of HIA practitioners, decisions around who gets scoped, resource pressures, and awareness of minority populations. These barriers figured extensively in the interviews and have been further analysed below.

7.7.1 SPECIFIC ATTITUDINAL BARRIERS TO PEOPLE WITH DISABILITIES

I first address the attitudinal barrier related to the HIA practitioners' understandings of disability that: 'the differences between the social and medical models of disability is not particularly well understood' (Interviewee B). As can be seen, some interviewees felt that HIA practitioners do not generally have a strong understanding of disability. This is similar to the issues discussed by Jongbloed and Crichton (1990) who write in the Canadian context about poor outcomes when policies are practised that are not written in the social model of disability. The quote from Interviewee B above is also not in accordance with objective six of the *New Zealand Disability Strategy* (2001) which the HIA guidelines (2005) have made a commitment to. This document states that our society should aim to 'foster an aware and responsive public service' (ODI, 2001, n/p). It would be assumed that practitioners would take this into account.

Some of the HIA experts also felt that the community at large had a weak understanding of disability: '...I think that disability is quite poorly understood across the board in New Zealand' (Interviewee B). I will argue in the next section that, in my view, this lack of understanding cannot be taken at face value. Instead, it must ask why there is such a lack of awareness of disability amongst the community at large when one in five people (20 percent) report as having a long term disability (ODI, 2001).

Interviewees felt that poor advocacy was a major reason that limits the inclusion of people with disability in the HIA process. They feel there are few community voices promoting disability in HIA. '...You should bring together as wide a group as possible... [and they prioritise the issues and determinants of health in an HIA]' (Interviewee B). This is a reason given as to why people

with disabilities are not fully involved in the HIA process. This issue advocates a need for higher awareness of the issues that people with disabilities face. As there may be parts of the population who do not receive this learning via their own contacts, it is important that awareness of this population be a mandatory part of education at school. This has been highlighted in the New Zealand Ministry of Education's *Special Education Review* (Ministry of Education, 2010) completed in 2010.

Interviewees also explained that the advocacy by HIA practitioners needs representation of people with disabilities in HIA, otherwise they are likely to be neglected: 'unless you start to be quite explicit about the nature of the inequality that you're seeking to address, then people with disabilities might well be not addressed at all' (Interviewee C). 'It must be a lack of understanding [as to why people with disabilities are not considered in HIA processes] because you have to be able to be concerned enough to say we've actually got to be sure that we're on the right path here, otherwise we're going to impact adversely on this group' (Interviewee D). The reason people with disabilities are not thought about is because of a 'social problem caused by a lack of social awareness' (Interviewee D).

A further reason for lack of inclusion for people with disability in the HIA process, is that they may not always be defined as a distinct group, but rather lumped together with other groups who have similar barriers, such as old people and mothers with prams. People with disabilities are 'not defined as a particular group in the recommendations of an HIA report, but maybe included under a label "for those for whom mobility is a challenge"' (Interviewee C). This maybe the reason that people with disabilities are not often defined in HIA reports. However, this is in contention with the commitment made to the social model of disability as a guiding framework of the HIA Guidelines (2005) (refer to section 6.2). This model advocates that people with disabilities are empowered to advocate for themselves. By lumping them in a group with others, they lose any power and independency.

The interviewees also stated that the advocacy that people with disabilities have for themselves is not strong and people with disability do not have a unified voice or strong political presence, which may be the reason they are not acknowledged in the HIA. 'There are no prominent spokespeople clearly identified with it.' [Unless there is]... 'representation of the groups that are doing it [people with disabilities] are often left on the outside' (Interviewee C). 'When their

[people with disabilities] issues are represented, that's generally how we manage to squeeze the money... [to assess them]' (Interviewee C). But HIA practitioners should not assume that people with disabilities will always feel safe to share their views. The unfortunate history that some people with disabilities have had to contend with may have left some of these people with a psychology where they may not feel confident enough to speak out for themselves (as explained in section 2.3.3).

HIA interviewees also thought that government advocacy for people with disabilities was a little uncertain and unclear. They felt disability did not really belong in the medical or social side of the government; it falls between the cracks and gets marginalised. '...[We can raise disability issues by] having more debate on how disability fits in' (Interviewee B). They also explained that New Zealand has a legislative duty to prioritise Māori and Pacifica. People with low incomes and children are also deemed to be important in the HIA process. However, disability is often left off the list of those that need to be scoped: '...[before the scoping process has even been completed]... they've already decided who the groups are they want to concentrate on and disability aren't often one of those groups'. 'People with disabilities have a lot of competition to get their nose in front – to be the population groups on the headlines' (Interviewee E). [If there is not] 'some requirement by legislation, or by representation in the groups that are doing it, then they are left on the outside' (Interviewee C.)

The government's commitment to people with disabilities was evident when writing the *New Zealand Disability Strategy* (2001), and this was a significant step for the rights of people with disabilities. The HIA guidelines (2005) also make reference to this document as a guiding framework. This reflects Carter and Markham's (2001) paper which explains that the social model of disability is the guiding theoretical framework for people with disabilities in a hospital in the United Kingdom. However, the theory of this model is not translated into practice and people with disabilities are subject to discrimination in the hospital (Carter and Markham, 2001).

The interviewees also highlighted that sometimes the methods used to consult people with disabilities in the scoping process may be why they had a questionable inclusion into the process. The format of information at the HIA workshops is not specific for the needs of the people with disabilities. 'There is not the same accessibility to resources in terms of people with visual impairment' [in the scoping meeting] (Interviewee A). 'Sometimes you need to be told directly,

this format doesn't work for me, could we try another way...?' (Interviewee E). 'Sometimes people doing the HIA might not think of going straight to a disability provider' (Interviewee A). In the United Kingdom, the discrimination that Carter and Markham (2001) write about as explained in section 6.3 can be seen in the form of inadequate resourcing to cater for people with impairments. They point to large print not being on offer to patients who have a visual impairment (Carter and Markham, 2001).

However, as demonstrated in table 4.1, the New Zealand HIA guidelines (2005) make a bold effort to bring awareness to people with disabilities in HIA processes. These guidelines present the strongest advocacy for people with disabilities; yet the practice of this advocacy is clearly not present, as demonstrated by the above research findings.

7.7.2 *GENERIC BARRIERS TO HIA*

The interviewees alluded to inadequate training, guidance and experience of HIA practitioners as a reason that may influence practitioner understanding of the social model of disability with respect to HIA procedures. 'I'm not sure how much emphasis the training gives on disability in particular...' (Interviewee B). '[What is focused on in HIA] is quite dependant on who is involved with it at the time' (Interviewee B). '[One HIA practitioner is] a dietician and he's passionate about health and well-being around food, exercise and quality of life' (Interviewee C).

As discussed earlier, one of the cited barriers to HIA is a lack of trained staff (Signal et al., 2006). It would be assumed that this would also be true if one were to conduct a disability assessment as part of an HIA. Trained staff would have to understand disability and the social model before they could embark on this task. It would be expected, however, that the training and guidance given to HIA practitioners would be based on the HIA guidelines (2005), which give ample consideration to people with disabilities.

The interviewees also felt that they could not advocate for one group (i.e., people with disabilities) too strongly in the training as it becomes boring to other trainees. 'There is evidence that if you talk to mainstream people about specific needs of minority groups, they cognitively lose interest'. 'We've got to be really careful that we don't turn people off' (Interviewee E).

Māori people are advocated for very strongly in the HIA process in New Zealand as indicated by several interviewees. The acknowledgement of Māori is obviously present in almost every HIA, and the repeated advocacy for this group has endorsed the consideration and acknowledgement they are given in HIA practice. This determination shows the power of advocacy in establishing recognition. Advocating for people with disabilities, similarly, may also endorse them as a population that deserves consideration.

The interviewees felt that the decision of who gets scoped in the HIA was largely dictated by those who funded the HIA. ‘Those who commission the HIA are the ones who have the final say of what goes in the HIA, what the focus is on and who gets scoped’ (Interviewee B). ‘So they decide who the priority groups are to get answers to questions they are really interested in’ (Interviewee E). It can be presumed that this part of the population would have to be thought about as their needs differ from that of mainstream society. As people with disabilities make up 20 percent of the New Zealand population (ODI, 2001), it would seem likely that this sector of the population would need attention in the HIA process.

The interviewees also alluded to the HIA practitioners having a part in the process of deciding who the priority groups are that need to be scoped, and often people with disabilities are not one of these groups. ‘[Each HIA practitioner]... approaches the HIA and the weight and value we give to different elements we give to any population that is subject to an HIA’ (Interviewee C).

Whatever their personal reasons, HIA practitioners should be committed to following the HIA guidelines that have been prescribed by the government in undertaking a HIA. The New Zealand HIA guidelines (2005) accentuate the importance of people with disabilities being involved in this process, as discussed in section 4.4. This is echoed by Puras (2009) who talks about the way that disability policies in Lithuania that are not practised in the social model of disability can negatively affect a child with a learning disability (Puras, 2009).

The interviewees also felt that who got scoped in the HIA process was dependent on who was in the scoping room as the community sets the agenda of the groups that need to be scoped. ‘[We ask the stakeholders]... who are the populations that are the most likely to be affected and who we need to involve in the subsequent stages of consultations?’ (Interviewee A). ‘[Prioritisation is influenced by the] ‘topic’ [of an HIA] (Interviewee E). ‘[Sometimes the constraint to thinking about people with disability is]...how much information can people absorb?’ (Interviewee E).

This is in contention with objective five of the *New Zealand Disability Strategy* (2001), which guides societies understanding of people with disabilities, stating that society must attempt to ‘foster leadership for people with disabilities’ (ODI, 2001). If people with disabilities are not a part of the scoping process of an HIA, they are effectively disabled from having any leadership role.

The interviewees felt strongly that lack of resources (time and money) prevents all population groups from being considered. ‘The twenty or thirty thousand it takes to do an HIA immediately put concerns/constraints on what one can do’ (Interviewee C). ‘...Time cost and lack of capacity [is what sometimes limits the inclusion of people with disabilities in the HIA process]’ (Interviewee D). ‘For the people running them, they think let’s just get everyone into a room and get this concentration done, and try and cover all the perspectives’ (Interviewee A). ‘Funding needs awareness’ [and this is largely a characteristic of the present government] (Interviewee C). In Signal et al.’s (2006) paper, funding is a major limitation to the implementation of the optimal methodology of the HIA process. This means that prioritisation of who can be part of this process is made and due to legislative commitments, people with disabilities are not one of these. But even if they were able to be one of these groups, it may be considered too costly to address the issues that people with disabilities face (which are a function of society, as described by the social model of disability). As Mansell (2008) writes, in Ireland, lack of funds may mean that when people with learning disabilities are being catered for, policies are often economically-focused (based on service provision) as opposed to person-centred (based on people with disabilities as defined by the social model of disability).

Interviewed HIA experts felt that minority groups (like people with disabilities) are left out until there is a specific formal procedural requirement such as the Whānau Ora tool to cater for them. ‘And of course Whānau Ora Impact Assessment¹¹ [requires us] to...look at particular populations’ (Interviewee D). ‘It is how consciously-aware they are of the need to assess for that particular population group’ (Interviewee E). The recognition of Māori is in line with the *Human Rights Act* (1993) (HRC, 1998), written specifically to protect the rights of minority groups in New Zealand

¹¹ The Whānau Ora Health Impact Assessment tool is a formal approach used to predict the potential health effects of a policy on Māori and their whānau. It pays particular attention to Māori involvement in the policy development process and articulates the role of the wider health determinants in influencing health and well-being outcomes (MoH, n/d).

(ethnicity/gender/disability). Even though people with disabilities are acknowledged in this act, surprisingly little effort is made to ensure their consideration in the HIA process.

The analysis of the interview findings has revealed a congruence between the specific attitudinal barriers to people with disability and the generic barriers to HIA in the literature (reviewed in the last section), compared with the empirical research findings presented in this chapter with respect to disability inclusion in HIA. However, I felt the interviews did not allude to any of the arguments that have been discussed in the ‘feminist interpretations of the creation of disability’ literature (as we saw in the previous chapter). These barriers, although not explicitly revealed verbally, arguably constitute the underlying discourse to the barriers identified in the conversations, as presented above.

I argue in the next two sections (sections 7.8 and 7.9) that a critically informed understanding can be gained of the reasons for the existence of the attitudinal and generic barriers revealed in the study findings by taking a step back and asking why the barriers identified in the HIA exist. Why is the difference between the social and medical models of disability not common knowledge amongst HIA practitioners and the wider community? If this was seen as an important social and political issue, it would very likely be much better understood by non-disabled people. This suggests that a process of denial is operating, as noted by Plumwood (1993, P. 48). It is likely that these exhibited behaviours are largely unconscious when people with disabilities are being treated as peripheral and unimportant, and most likely a product of social norms. This is in spite of the fact that a large minority of the community has some disability, and also that this tool aims to understand the ways that policy affects disadvantaged parts of the population, such as those with disabilities. However, generic usage of concepts such as ‘he was blind and deaf to my arguments’ show that disability plays an important role in defining identities negatively. Examples of the underlying ‘feminist interpretations of the construction of disability’ barriers, which potentially constitute the deep-seated, meta analysis of the identified barriers, are presented below.

7.8 REVIEW OF ATTITUDINAL BARRIERS FROM A FEMINIST PERSPECTIVE

7.8.1 UNDERSTANDING OF DISABILITY

7.8.1.1 By HIA practitioners

The practitioner's understanding of the social model would shape their attitude and approach to according recognition to people with disabilities in HIA.

"The differences between the social and medical models of disability is not particularly well understood"

(Interviewee B).

The understanding of the social model of disability is integral to the HIA practitioners being able to adequately cater for people with disabilities in the HIA. If they do not have a comprehension of this model, the question is why this is the case? Is their perceived value of people with disabilities low? Do they not see them as an important part of the HIA process? Do they see them as 'the other'? Mechanisms of hyper-separation, or denial could explain the quotation above. Hyper-separation in this context would involve HIA practitioners perceiving the issues that people with disabilities contend with as so far removed from the 'norm' that they do not warrant consideration. Denial could also provide an explanation to this comment, as people with disabilities maybe viewed as the dependant background, and this rationalises denying the importance of their needs (Plumwood, 1993).

7.8.1.2 By the Community

Poor understanding by the community of the social model view of disability.

"With the social medical model again I think that disability is quite poorly understood across the board in New Zealand" (Interviewee B).

Do people in the community choose not to know about people with disability? Perhaps this is because they do not acknowledge them as an important part of society? Maybe they see them as 'the other' and the mechanisms of denial and hyper-separation are operating much like they do above. Furthermore, the assumption by interviewees that the social model is poorly understood in practice constructs disability as a peripheral or

unimportant area of focus in the community when this may not be the case. It was a conflict between the social and medical models of disability which led Parlais (2009) to find a barrier to implementation of deinstitutionalisation (discussed in section 6.3). A similar conflict is operating here.

7.8.2 ADVOCACY

7.8.2.1 Community Advocacy

There are few community voices promoting disability in HIA.

“You bring together as wide a group as possible...[and they prioritise the issues and determinants of health in an HIA]” (Interviewee B).

In this context, hyper-separation maybe working a little differently to the example above, as advocacy is an action which aims to bring awareness to those who are under-represented (such as people with disabilities). However, people with disabilities may be perceived as having needs so far from the ‘norm’ in that their needs are put in the background or ‘forgotten’ (Plumwood, 1993).

7.8.2.2 HIA Practitioners Advocacy

Without advocacy for people with disabilities, they are often neglected in HIA practice.

“Unless you start to be quite explicit about the nature of the inequality that you’re seeking to address, then people with disabilities might well be not addressed at all” (Interviewee C).

Cognitively HIA practitioners forget about people with disability unless they are a focus of the HIA.

“It must be a lack of understanding [as to why people with disabilities are not considered in HIA processes]... because you have to be able to be concerned enough to say we’ve actually got to be sure that we’re on the right path here, otherwise we’re going to impact adversely on this group” (Interviewee D).

The social awareness of people with disability is questionable and this means that they are often not thought about.

“[The reason people with disabilities are not thought about is because of a]... social problem caused by a lack of social awareness” (Interviewee D).

Why is there a lack of awareness of people with disabilities in the practice of the HIA process when they are considerably acknowledged in the HIA guidelines? Why do people with disabilities need someone advocating for them to endorse their inclusion in the process? Do HIA practitioners not feel that people with disabilities are a valuable part of society, and need to be part of the HIA process? It might be suggested that they have little interest in catering for these people because they see them as ‘the other’ and not deserving of consideration as a full part of society. These processes of ‘othering’ do not occur because of bad intentions on the part of individuals. Rather, they are grounded in culturally and socially constructed ideas about the ‘norm’ and the ‘other’.

A further example of this lack of advocacy by HIA Practitioners is when people with disabilities are often not defined as a distinct group in the documented HIA scoping process, but rather lumped together with other groups who have similar barriers, such as old people and mothers with prams. ‘[People with disabilities are] not defined as a particular group in the recommendations of an HIA report, but maybe included under a label ‘for those for whom mobility is a challenge’ (Interviewee C). By acknowledging people with disabilities as a distinct group, are the HIA practitioners empowering people with disability and taking power away from the practitioners? (see section 6.3). This practice of ‘lumping’ those with mobility issues together may be explained by the mechanism of homogeneity. By not acknowledging that people with disabilities have a unique set of needs, ignorance of HIA practitioners about this population is rationalised (Plumwood, 1993).

7.8.2.3 Self Advocacy

People with disability do not have a unified voice or strong political presence.

“There are no prominent spokespeople clearly identified with it” (Interviewee C).

People with disabilities need to be specifically recruited as forum members.

“[Unless there is] representation of the groups that are doing it, [people with disabilities] are often left on the outside” (Interviewee C).

We need people with disability to really involve themselves and advocate for themselves.

“When their [people with disabilities] issues are represented that’s generally how we manage to squeeze the money [to include them in the assessment]” (Interviewee C).

HIA Practitioners are calling for people with disabilities to represent themselves in the HIA process. If they had a basic level of awareness, they would understand that it is not easy for people with disabilities to speak out loud (as described in section 2.3.1 of the literature review) as they may have low levels of confidence. Taking interest in and understanding people with disabilities, as is the case with Māori people, would be a valuable asset. Is the disinterest to make themselves aware because of the process of ‘othering’? If the process of ‘othering’ was not taking place, it would be more possible to think specifically about affordable ways of recruiting and involving people with disabilities in the HIA scoping process.

7.8.2.4 Government Advocacy

Disability does not really belong in the medical or social side of the government; it falls between the cracks and gets marginalised.

“[We can raise disability issues by] having more debate on how disability fits in” (Interviewee B).

New Zealand has a legislative duty to prioritise Māori, Pacifica and low income people and children are also deemed as important and disability is often left off the list of those that need to be scoped.

“[Before the scoping process has even been completed] they’ve already decided who the groups are they want to concentrate on and disability aren’t often one of those groups” (Interviewee C).

People with disability do not have a very big voice and there is often a lot of competition for voices to be heard. In New Zealand, there is a legal obligation to hear Māori and

Pacifica voices. ‘People with disabilities have a lot of competition to get their nose in front – to be the population groups on the headlines’ (Interviewee E).

Unless there is some legislative mandate, people with disability will not be on the public policy agendas, including the HIA agenda.

“[If there is not] some requirement by legislation, or by representation in the groups that are doing it, then they are left on the outside” (Interviewee C).

The above reasons can explain that when government commitment to disability is not present, the HIA practitioners do not have an awareness of people with disability. The

New Zealand government has obligations to practice the principles of the *Disability Strategy* (2001), the *Human Rights Act* (2003) and the *United Nations Convention on the Rights of Persons with Disabilities* (2007). These three documents emphasise the rights of people with disabilities. Even with the legislative requirement people with disabilities are still left on the periphery of the HIA process. This may be because they are treated as ‘the other’.

7.8.3 INADEQUATE CONSULTATION

The format of information at the HIA workshops needs to be specific for the needs of the people with disabilities.

“There is not the same accessibility to resources in terms of people with visual impairment [in the scoping meetings]” (Interviewee A).

Often, the practitioners do not think about people with disabilities having specific needs the way the Māori do.

“Sometimes you need to be told directly, this format doesn’t work for me, could we try another way” (Interviewee E).

No specific disability HIA workshops have ever been held. More could be done to involve people with disabilities in HIA.

“Sometimes people doing the HIA might not think of going straight to a disability organisation” (Interviewee A).

Inappropriate consultation contributes to proliferation of a lack of awareness. It may be due to disinterest in people with disabilities as they are perceived as being so far removed from the ‘norm’, or because by not allowing them to participate in the scoping process, they are kept dependant and disempowered (see section 6.3). As the mechanism of homogeneity explains, by ignoring the needs of people with disabilities, which may differ from the mainstream, ignorance of the needs of this population are rationalised (Plumwood, 1993).

7.9 REVIEW OF GENERIC BARRIERS FROM A FEMINIST PERSPECTIVE

7.9.1 TRAINING/GUIDANCE/EXPERIENCE OF HIA PRACTITIONERS

Training and guidance may influence the understanding of the social model by a practitioner.

“I’m not sure how much emphasis the training gives on disability in particular” (Interviewee B).

Consideration of people with disabilities is reliant on the expertise of who is doing the HIA and whether disability is something they know about.

“[What is focused on in HIA] is quite dependant on who is involved with it at the time” (Interviewee B).

The practitioner’s personal passions influence the way they conduct their HIA practice.

“[One practitioner] is a dietician and he’s passionate about health and well-being around food, exercise and quality of life” (Interviewee E).

Why when other disadvantaged groups are highlighted in this training are people with disabilities not given the same consideration? As Interviewee C states: ‘in the training, there is not a lot of emphasis on disability’. The HIA guidelines have been written to endorse the rights to health that disadvantaged groups, such as people with disabilities, have when they are governed under societal policies. However, people with disabilities

are not privileged to the same rights in the HIA process as other parts of the population as demonstrated in section 4.5. This may be because people with disabilities have been left on the periphery of the training that HIA practitioners receive. Is this because people with disability are treated as ‘the other’?

7.9.2 CANNOT ADVOCATE FOR ONE GROUP TOO STRONGLY

When providing training, one group cannot be advocated too strongly as it becomes boring to other trainees.

“There is evidence that if you talk to mainstream people about specific needs of minority groups, they cognitively lose interest”. “We’ve got to be really careful that we don’t turn people off” (Interviewee E).

The process of ‘othering’ exhibited here in relation to the mechanism of instrumentalism makes the assumption is that the needs and desires of people with disabilities are not important in relation to those of the wider community. This rationalises their disregard by the community.

7.9.3 DECISION ABOUT WHO GETS SCOPED

(a) Funders

Those who commission the HIA are the ones who have the final say of what goes in the HIA, what the focus is on and who gets scoped.

“So they decide who the priority groups are to get answers to questions they are really interested in” (Interviewee E).

Funding pressures affect resources to conduct an HIA. The funding that is obtained to conduct an HIA is directly related to how much value is placed on the populations involved in the process. If there is not enough money to undertake assessment of people with disability in an HIA, the value placed on making life equitable for this population must not be considered highly as explained by the process of ‘othering’. This maybe further explained by the mechanism of denial. The funders of an HIA can cognitively ‘deny’ the existence of people with disabilities and rationalise this by the perceived back-grounding this population play in society (Plumwood, 1993).

(b) HIA Practitioners

The priority populations that need to be assessed are largely decided before the practice of the scoping exercise takes place. Disability groups are not considered as one of those priority groups.

“[Each HIA practitioner] approaches the HIA and the weight and value we give to different elements we give to any population that is subject to an HIA” (Interviewee C).

This explanation reveals that some HIA practitioners do not even give people with disability the option of being one of the priority populations in an HIA. This is a definite endorsement of ‘the other’ mechanisms at work.

The priority populations are set by precedent and legislation. The recently negotiated *United Nations Convention on the Rights of Persons with Disabilities* (2007) has been signed by New Zealand, and advocates that people with disabilities should become one of the priority groups. This change has not yet found its way through to HIA practitioners.

(c) Scoping Community

Depends on who is in the scoping room as the community sets the agenda of the groups that need to be scoped.

“[We ask the stakeholders] who are the populations that are the most likely to be affected and who we need to involve in the subsequent stages of consultations?” (Interviewee A).

Depends on what the issue is and the big concerns in the community are at the time as to what the stakeholders prioritise.

[Prioritisation is influenced by the] “topic” [of an HIA] (Interviewee E).

As HIA requires feedback from the Community about different groups in reaction to different health determinants, there is a large amount of information communicated.

[Sometimes the constraint to thinking about people with disability is] “how much information can people absorb” (Interviewee E).

This explanation seeks to take the onus off the practitioner and put it on the scoping community. If this were 100 percent true, the comment from one practitioner who stated that ‘It is my job to advocate for the groups whose voices aren’t heard’ would mitigate this as being an explanation.

7.9.4 RESOURCE PRESSURES

Lack of resources (time/money) prevents all groups being thought about.

“The twenty or thirty thousand it takes to do an HLA immediately put concerns/constraints on what one can do”
(Interviewee C).

Time and resource pressures mean that people with disability are not prioritised.

“Time cost and lack of capacity [is what sometimes limits the inclusion of people with disabilities in the HLA process]” (Interviewee D).

Funding pressures mean that all groups cannot be assessed according to the format that is most appropriate for them. “For the people running them, they think let’s just get everyone into a room and get this concentration done, and try and cover all the perspectives. I think... it would be particularly from a disability perspective, great to have a fixed discussion with a group of people which concentrated on those issues”
(Interviewee A).

“Funding needs awareness” [and this is largely a characteristic of the present government] (Interviewee C).

These barriers can be described similarly to the mechanisms of ‘othering’ defined as explanations to funding pressures in the attitudinal barriers above. The mechanism which may better underpin these comments could be hyper-separation or denial.

7.9.5 AWARENESS OF MINORITY GROUPS

Minority groups are left out until there is a specific formal procedural requirement such as the Whānau Ora tool.

“And of course Whānau Ora impact assessment, and so they are...looking at particular populations”

(Interviewee D).

“It is how consciously-aware they are of the need to assess for that particular population group” (Interviewee E).

Historically, Māori have been a group who have been ‘othered’ in New Zealand based on their values which differ from the mainstream population of New Zealand. But a process of foregrounding Māori perspectives has taken place, aided by activism, legislation and the creation of specific tools such as the Māori Whānau Ora model of health. These have made the ‘othering’ of Māori less possible within the HIA. A similar process could take place in relation to disability.

The above investigation has presented a critical feminist informed analysis of all the defined themes found in the empirical findings. The explanation has focused on different mechanisms of ‘otherness’ explanations as defined by the ‘feminist interpretations of the construction of disability’ literature.

7.10 CONCLUDING COMMENTS

In conclusion, the purpose of the second research question was to understand factors that influence the gap between policy and practice in HIA procedures relating to disability. This chapter has addressed that objective by highlighting from a bottom-up perspective the key empirical findings related to this question which emerged from in-depth conversations with five experienced HIA professionals. These themes have been related to the literature that can explain the gap between policy and practice of HIA relating to people with disabilities. Though both the ‘specific attitudinal barriers to people with disabilities’ and the ‘generic HIA barriers’ have been highlighted, the ‘feminist interpretations of the construction of disability’ barriers have not been as obvious. However, it can be argued that the ‘feminist interpretations of the construction of disability’ literature, which discusses the mechanisms that lead to a social construction of disability, can underpin all the identified barriers. This factor needs to be addressed to change the recognition of people with disabilities in HIA practice.

The concluding chapter to this study will sum up the research findings of this study and discuss the wider theoretical significance of the findings.

CHAPTER 8: SUMMARY AND CONCLUSIONS

8.1 INTRODUCTION

In this final chapter, I will summarise the research findings and draw some conclusions I have arrived at during this study. This will be followed by recommendations to address the poor awareness of disability issues in HIA practice.

- Section 8.2 summarises the research findings and reflects on the theoretical significance of the findings from the perspective of the social model of disability.
- Section 8.3 presents conclusions that have been reached after the completion of this research.
- Section 8.4 suggests policy implications for improving HIA practice in New Zealand.
- Section 8.5 gives recommendations to ameliorate the problem.
- And finally section 8.7 presents a reflection on this research through my own personal disability journey.

8.2 SUMMARY OF RESEARCH FINDINGS

The objective of this study was to understand to what extent disability awareness was manifest in HIA practice in New Zealand and what factors affected this relationship. Two research questions were defined to achieve this research objective:

- (a) What is the relationship between policy and practice regarding disability awareness in New Zealand?
- (b) What factors influence this relationship?

I shall discuss these two questions separately.

(A) WHAT IS THE RELATIONSHIP BETWEEN POLICY AND PRACTICE REGARDING DISABILITY AWARENESS IN NEW ZEALAND?

With respect to the first question, the research findings have established that there is a gap between policy and practice in disability awareness in New Zealand's HIA field. In contrast with a selection of three other assessed Anglophonic countries: England, Scotland, and Australia, the New Zealand HIA guidelines show a high awareness of people with disabilities in the HIA process, and are informed by the social model of disability. According to this model, disability is a social construct enforced by the wider society on those with impairments such as blindness. One would thus expect HIA practitioners in New Zealand to recognise this when undertaking HIAs. However, a qualitative, top-down analysis of HIA reports showed that New Zealand HIA assessments rank lower compared with other similar countries in terms of inclusion of people with disabilities.

(B) WHAT FACTORS INFLUENCE THIS RELATIONSHIP?

With respect to the second research question, the research findings based on in-depth conversations with five HIA experts demonstrate that the poor awareness of people with disabilities in HIA practice is a function of a myriad of both formal and informal institutional barriers. Many of these barriers are deep-seated in Anglophonic societies. This finding was reached following a thematic analysis of the barriers to disability recognition in HIA, extrapolated from interviews, and constituted 'attitudinal barriers towards people with disabilities' barriers and 'Generic barriers to HIA'. However, it was noted that the 'feminist interpretations of the construction of people with disabilities' barrier was not alluded to in the interviews. Subsequently, I presented an argument that the 'feminist interpretations of the construction of people with disabilities' potentially underpin all the other identified barriers. As discussed in the next section, this finding has theoretical implications for implementation of the tenets of the social model of disability as a policy framework.

8.3 CONCLUSIONS

In this section, I will review the significance of the research findings from the perspective of the social model of disability.

As noted earlier, according to the social model of disability, disability is a socially constructed barrier enforced by the wider society on those with impairments. Hence, one of its key tenets is the need for inclusion. Used as a policy construct, one would expect HIA practitioners to be cognisant of the discriminatory barriers people with disabilities face; a function of social policies and the importance of being inclusive of these people in HIA practice. New Zealand HIA procedures are innovative and comprehensive in recognising this. However, this policy has proved difficult to put into practice, as demonstrated by the findings of this study. Some of the barriers revealed in this study are generic to all fields of HIA but many of the more important ones are attitudinal, as explained by the ‘feminist interpretations of the construction of disability’ literature and are specific to the disability sector.

Hence, the conclusion of this thesis is that the social model of disability is not being recognised in HIA practice in New Zealand due to the reasons defined by the ‘feminist interpretations of the construction of disability’ and instead focuses on ‘otherness’ perceptions of people with disabilities. This provides insight into the reasons for the HIA rhetoric and implementation gap identified in this study.

The above conclusion raises questions about the usefulness of the social model of disability as a policy construct. Based on the findings of this study, one could argue that in Western democracies such as New Zealand, there are deep-seated institutional barriers which make it difficult to break down socially imposed barriers on people with disabilities and which make everyday living a major challenge for these people. It is clear, therefore, that for New Zealand HIA procedures to be effective from the perspective of people with disabilities, we need to undertake wide-ranging societal changes to ameliorate the social barriers faced by people with disabilities.

8.4 POLICY AND PRACTICE: SIGNIFICANCE OF RESEARCH FINDINGS

HIA is a policy tool that could potentially alert policy makers to the negative impacts that their policies can have on people with disabilities and hence remedy this to ameliorate those impacts. This research has come to some very important conclusions about the practice of disability awareness as part of this tool, and raises some very pertinent issues that need to be attended to at a national policy level in order for New Zealand to fulfil the goals of the *New Zealand Disability Strategy* (2001) and the *United Nations Convention on the Rights of Persons with Disabilities* (2007).

New Zealand led the negotiations for this convention, and signed up to on 30th March 2007. These issues are namely that there are barriers which are preventing disability awareness being practiced in HIA. There have been many reasons given for this apparent lack, which are all potentially underpinned by deep-seated, attitudinal barriers constructed by society, and therefore can only be addressed by institutional change. The research presented here has added to the literature in existence on these issues.

These issues need to be addressed at a policy level, as equity within society is a universal goal of Western societies, and disparities that one population face cannot be rationalised by the lack of awareness that is shown by society. More specifically, a lack of awareness based on the poor understanding of the barriers disabled people face, and their needs which differ from the mainstream does not rationalise their poor recognition in the HIA process.

Arguably, disability in the context of the HIA process is a microcosm of disability in the context of wider societal issues. The same recommendations that have come out of this research could also be applied to other parts of society, and may help to address the disparities that people with disability face.

8.5 RECOMMENDATIONS

The recommendations that are presented below are based on discussions with many people during the course of this study:

- **There needs to be a specific disability assessment tool.**

This tool could be utilised much like the Māori Whānau Ora Impact Assessment, which specifically assesses Māori health. Though this would encourage HIA practitioners to undergo disability assessment as part of their HIA, as Interviewee D pointed out, ‘disability assessment should be a part of every HIA’, and should not be performed only in some cases when this model is used.

- **HIA guidelines need to be rewritten.**

The HIA guidelines need to be rewritten to make more explicit the method that needs to be deployed when undergoing consultation with people who have disability. This would be of great help as people with disabilities have needs which differ to other populations, and as

these needs are not well defined and not very well understood, it would be helpful for HIA practitioners if they were defined in the guidelines to achieve a comprehensive engagement in the scoping process.

- **Greater take-up of HIA by NGO sector.**

HIA is typically practiced in the government sector. Issues such as disability are presently not issues that are focused on by the government sector. It may thus be a very beneficial step to introduce HIA into the NGO sector. This arguably may present a bigger opportunity and contribution to increase disability awareness in the HIA process.

- **There is a need to make connections and train specific disability advocates who can conduct focus groups with people who have disabilities.**

This is a recommendation based on the current HIA process. People with disabilities may be hard to engage with when time to build relationships with HIA practitioners is not available. Therefore, it would be more beneficial to train a disability advocate into the role of someone who can scope a focus group of people with disabilities to understand the issues that they face in a particular HIA.

- **There should be a conscious effort to invite people with disabilities to the scoping meetings.**

This idea is also based on the current HIA process which makes recommendations based on the scoping process. This is another awareness issue about people with disabilities. Some may not come to a meeting unless personally invited, but the HIA practitioners who facilitate the meetings need to be aware that people with disabilities have this characteristic. This is one of the many issues that could be addressed with a disability awareness campaign.

- **More people with disabilities need to be proactive in taking part in this process.**

Though there are some major inadequacies in the HIA process which limit people with disabilities from participating, people with disabilities can help to ameliorate the seclusion they may feel in the process by actively getting involved. But it also must be acknowledged that people with disabilities may not be able to take this step as their historical discrimination has left many feeling disempowered (as explained in section 2.3.1).

Interviewee C told me that just by talking to him about the HIA process in relation to disability he had become conscious about how he might change his practice.

- **There needs to be disability specific focus groups for people with varying impairments.**

This, again, is a recommendation based on the scoping process and is yet another awareness issue about people with disabilities. People with disabilities generally will not talk in a big group. They may feel that their contribution is not of value by the other members when they are in a group format, and they will not disagree with the mainstream suggestion even if the suggestion will pose an adverse situation for themselves. They may do this in an effort not to be disagreeable (see section 2.3.1). It may take a one-on-one meeting or disability specific focus if people with disabilities are to give honest feedback.

- **There should not be a reliance on the ‘old people’ proxy to cover all disability needs.**

This again, is a recommendation based on the scoping process. This is yet another awareness issue about people with disabilities. People with disabilities are vastly diverse and different in their needs. There is no ‘generic’ disability, and by only catering for ‘old people’ there is a risk of neglecting to cater for many other people who have different disabilities and different needs.

- **There is a need to build relationships with people with disabilities.**

This is a further recommendation based on the scoping process to do with awareness issues about people with disabilities. People with disabilities may be honest with few people. This is because they have been taught to be grateful for whatever they receive during their lives as they are asking for ‘extra’ accommodations when they ask for resources to be made accessible. Some people with disabilities need to spend time and become familiar with anyone they are going to ask to provide accommodations which will make resources accessible. This also means that HIA practitioners need more time and resources for the scoping workshop to allow this to happen.

- **There is a need to find suitable facilities to accommodate people with disabilities for the scoping workshops.**

This again, is a recommendation based on the scoping process. This is yet another awareness issue about people with disabilities. Accessibility issues are perhaps the best publicised and understood issues that people with disabilities face. Obviously, when undertaking a meeting to which people with disabilities may be asked to participate, there needs to be effort to make these facilities available. This means that all the impairments of

people who are participating may need to be catered for, which could be sensory impairments such as hearing, or sight, as well as wheelchair user access.

- **There is a need for a national awareness campaign promoting people with disabilities.**

The need for an awareness campaign was suggested by a few people in the course of this research. A mental-health awareness raising campaign, 'Like minds like mine' in its latest audit (2011), has shown a four percent increase in mental health awareness in the population. Arguably, this has had tangible outcomes such as an increased employment rate for people with mental health issues (Mental Health Foundation, 2011).

Arguably, this idea could address informal institutional barriers and hence could solve all the reasons that have been given to try and explain the reasons people with disabilities are sometimes not well assessed in the HIA process. A national awareness campaign could potentially change the way society view those with disabilities, and the value they place on accommodating them. In terms of HIA practice, this could change the resources and priorities defined by the funders of HIAs to include people with disabilities in their processes. It could change who the community that take part in the scoping process identify as an affected population, and who needs assessment. It could change the emphasis that the HIA practitioners place on certain populations when they suggest and advocate on behalf of in the HIA process, and it could also encourage the HIA practitioners to think about accommodations for people with specific disabilities instead of lumping them in with older people and other mobility impaired groups. But, potentially the most valuable impact this campaign could have is to change attitudes towards people with disabilities, and make understood that people with impairments are only disabled by the society they live in. It is hoped that this awareness would also be communicated to policy makers and increase legislation about people with disability.

Oliver states that policy practitioners have "internalized the dominant individualistic world view, and do not even see themselves as being oppressive" (Oliver, 1995). He also feels that a higher awareness and level of attention that policy makers give disability issues will only change through legislation. He believes this changes behaviour, as opposed to awareness raising campaigns which only change attitudes. This is the basis of the next recommendation presented here:

- **Implement consequential legislation to ensure people with disabilities have equal health and wellbeing to all other members of society.**

As discussed in this thesis, there is little legislation to back up policies to ensure HIA is inclusive of people with disabilities. Much like the *New Zealand Disability Strategy* (ODI, 2001), this recommendation aims to increase the acknowledgement and value of people with disabilities by making it a legislative requirement.

8.6 FUTURE RESEARCH RECOMMENDATIONS

There are some obvious gaps in the literature regarding both disability and HIA that warrant further investigation. People with disabilities are not very well acknowledged in legislation in New Zealand. The reasons for this are not well defined, and though there may have been research undertaken, government has been slow to translate these findings into policy and good practice recommendations. There needs to be further research to understand what barriers influence this.

I also feel that specifically looking at disability in the context of HIA would be a beneficial research recommendation. As agreed upon by several of the interviewees I talked to, HIA, when practiced correctly, can potentially diagnose shortfalls of policy which disadvantage people with disabilities. This is a very valuable tool, and rationalises extra research into how the findings of this study can be translated into practical conduct in HIA practice.

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APPENDIX A: NEW ZEALAND DISABILITY STRATEGY

The Government's Objectives:

Fifteen Objectives have been developed for the New Zealand Disability Strategy.

Objective 1: Encourage and educate for a non-disabling society

- **Encourage the emergence of a non-disabling society that respects and highly values the lives of disabled people and supports inclusive communities.**

Objective 2: Ensure rights for disabled people

- **Uphold and promote the rights of disabled people.**

Objective 3: Provide the best education for disabled people

- **Improve education so that all children, youth and adult learners will have equal opportunities to learn and develop in their local, regular educational centres.**

Objective 4: Provide opportunities in employment and economic development for disabled people

- **Enable disabled people to work in the open labour market (in accordance with human rights principles) and maintain an adequate income.**

Objective 5: Foster leadership by disabled people

- **Acknowledge the experience of disability as a form of specialised knowledge and strengthen the leadership of disabled people.**

Objective 6: Foster an aware and responsive public service

- **Ensure that government agencies, publicly funded services and publicly accountable bodies (such as territorial authorities) are aware of and responsive to disabled people.**

Objective 7: Create long-term support systems centred on the individual

- **Create a quality assessment and service delivery system that is centred on disabled people, ensures their participation in assessment and service delivery, has invisible borders and is easy to access.**

Objective 8: Support quality living in the community for disabled people

- **Provide opportunities for disabled people to have their own homes and lives in the community.**

Objective 9: Support lifestyle choices, recreation and culture for disabled people

- **Create and support lifestyle choices for disabled people within the community and promote access to recreation and cultural opportunities.**

Objective 10: Collect and use relevant information about disabled people and disability issues

- **Improve the quality of relevant disability information collected, analysed and used, including regular national surveys of activity limitation.**

Objective 11: Promote participation of disabled Maori

- **Promote opportunities for disabled Maori to participate in their communities and access disability services. Disabled Maori should receive an equitable level of resource that is delivered in a culturally appropriate way.**

Objective 12: Promote participation of disabled Pacific peoples

- **Promote opportunities for disabled Pacific peoples to participate in their communities and access disability services. Disabled Pacific peoples should receive an equitable level of resource that is delivered in a culturally appropriate way.**

Objective 13: Enable disabled children and youth to lead full and active lives

- **Disabled children and youth should enjoy full and active lives, in conditions that prepare them for adulthood and which:**

- ensure their dignity
- affirm their right to a good future and to participate in education, relationships, leisure, work and political processes
- recognise their emerging identities as individuals and reinforce their sense of self
- promote self-reliance
- recognise their important links with family, friends and school
- facilitate their active participation in the community.¹

Objective 14: Promote participation of disabled women in order to improve their quality of life

- **Improve opportunities for disabled women to participate in their communities, access appropriate disability services, and improve their quality of life.**

Objective 15: Value families, whānau and people providing ongoing support

- **Acknowledge and support the roles, responsibilities and issues facing family, whānau and those who support disabled people.**

Developed from Article 23 of the United Nations Convention on the Rights of the Child.

APPENDIX B: UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Article 1 - Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Article 2 - Definitions

For the purposes of the present Convention:

* "Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

* "Language" includes spoken and signed languages and other forms of non spoken languages;

* "Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

* "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

* "Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Article 3 - General principles

The principles of the present Convention shall be:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 4 - General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:

1. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
2. To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
3. To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
4. To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
5. To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
6. To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;

7. To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

8. To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;

9. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.

Article 5 - Equality and non-discrimination

1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 6 - Women with disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 7 - Children with disabilities

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Article 8 - Awareness-raising

1. States Parties undertake to adopt immediate, effective and appropriate measures:
 1. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
 2. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
 3. To promote awareness of the capabilities and contributions of persons with disabilities.

Measures to this end include:

1. Initiating and maintaining effective public awareness campaigns designed:

1. To nurture receptiveness to the rights of persons with disabilities;
2. To promote positive perceptions and greater social awareness towards persons with disabilities;
3. To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
2. Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
3. Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
4. Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Article 9 - Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

1. Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
2. Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:

1. Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
2. Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
3. Provide training for stakeholders on accessibility issues facing persons with disabilities;
4. Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

5. Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

6. Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

7. Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

8. Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 10 - Right to life

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 11 - Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Article 12 - Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 13 - Access to justice

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 14 - Liberty and security of the person

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:

1. Enjoy the right to liberty and security of person;
2. Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Article 16 - Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 17 - Protecting the integrity of the person

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 18 - Liberty of movement and nationality

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:

1. Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;

2. Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;

3. Are free to leave any country, including their own;

4. Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

1. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

2. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

3. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 20 - Personal mobility

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

1. Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;

2. Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;

3. Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;

4. Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Article 21 - Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive

and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

1. Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
2. Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
3. Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
4. Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
5. Recognizing and promoting the use of sign languages.

Article 22 - Respect for privacy

1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.
2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 23 - Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
 1. The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
 2. The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
 3. Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Article 24 – Education

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

1. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

2. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

3. Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

1. Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

2. Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

3. Reasonable accommodation of the individual's requirements is provided;

4. Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

5. Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

1. Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

2. Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

3. Ensuring that the education of persons, and in particular children, who are blind, deaf or deaf/blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

1. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

2. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

3. Provide these health services as close as possible to people's own communities, including in rural areas;

4. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

5. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

6. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26 - Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

1. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

2. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 27 - Work and employment

1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

1. Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

2. Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;

3. Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;

4. Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;

5. Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

6. Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;

7. Employ persons with disabilities in the public sector;

8. Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

9. Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

10. Promote the acquisition by persons with disabilities of work experience in the open labour market;

11. Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

Article 28 - Adequate standard of living and social protection

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

1. To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;

2. To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

3. To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;

4. To ensure access by persons with disabilities to public housing programmes;

5. To ensure equal access by persons with disabilities to retirement benefits and programmes.

Article 29 - Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

1. Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

1. Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

2. Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

3. Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

2. Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

1. Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

2. Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

Article 30 - Participation in cultural life, recreation, leisure and sport

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:

1. Enjoy access to cultural materials in accessible formats;

2. Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;

3. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.

3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:

1. To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;

2. To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;

3. To ensure that persons with disabilities have access to sporting, recreational and tourism venues;

4. To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;

5. To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

Article 31 - Statistics and data collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

1. Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

2. Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Article 32 - International cooperation

1. States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities. Such measures could include, inter alia:

1. Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;

2. Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;

3. Facilitating cooperation in research and access to scientific and technical knowledge;

4. Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.

2. The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.

Article 33 - National implementation and monitoring

1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

Article 34 - Committee on the Rights of Persons with Disabilities

1. There shall be established a Committee on the Rights of Persons with Disabilities (hereafter referred to as “the Committee”), which shall carry out the functions hereinafter provided.

2. The Committee shall consist, at the time of entry into force of the present Convention, of twelve experts. After an additional sixty ratifications or accessions to the Convention, the membership of the Committee shall increase by six members, attaining a maximum number of eighteen members.

3. The members of the Committee shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the present Convention. When nominating their candidates, States Parties are invited to give due consideration to the provision set out in article 4.3 of the present Convention.

4. The members of the Committee shall be elected by States Parties, consideration being given to equitable geographical distribution, representation of the different forms of civilization and of

the principal legal systems, balanced gender representation and participation of experts with disabilities.

5. The members of the Committee shall be elected by secret ballot from a list of persons nominated by the States Parties from among their nationals at meetings of the Conference of States Parties. At those meetings, for which two thirds of States Parties shall constitute a quorum, the persons elected to the Committee shall be those who obtain the largest number of votes and an absolute majority of the votes of the representatives of States Parties present and voting.

6. The initial election shall be held no later than six months after the date of entry into force of the present Convention. At least four months before the date of each election, the Secretary-General of the United Nations shall address a letter to the States Parties inviting them to submit the nominations within two months. The Secretary-General shall subsequently prepare a list in alphabetical order of all persons thus nominated, indicating the State Parties which have nominated them, and shall submit it to the States Parties to the present Convention.

7. The members of the Committee shall be elected for a term of four years. They shall be eligible for re-election once. However, the term of six of the members elected at the first election shall expire at the end of two years; immediately after the first election, the names of these six members shall be chosen by lot by the chairperson of the meeting referred to in paragraph 5 of this article.

8. The election of the six additional members of the Committee shall be held on the occasion of regular elections, in accordance with the relevant provisions of this article.

9. If a member of the Committee dies or resigns or declares that for any other cause she or he can no longer perform her or his duties, the State Party which nominated the member shall appoint another expert possessing the qualifications and meeting the requirements set out in the relevant provisions of this article, to serve for the remainder of the term.

10. The Committee shall establish its own rules of procedure.

11. The Secretary-General of the United Nations shall provide the necessary staff and facilities for the effective performance of the functions of the Committee under the present Convention, and shall convene its initial meeting.

12. With the approval of the General Assembly, the members of the Committee established under the present Convention shall receive emoluments from United Nations resources on such terms and conditions as the Assembly may decide, having regard to the importance of the Committee's responsibilities.

13. The members of the Committee shall be entitled to the facilities, privileges and immunities of experts on mission for the United Nations as laid down in the relevant sections of the Convention on the Privileges and Immunities of the United Nations.

Article 35 - Reports by States Parties

1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.
2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.
3. The Committee shall decide any guidelines applicable to the content of the reports.
4. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to consider doing so in an open and transparent process and to give due consideration to the provision set out in article 4.3 of the present Convention.
5. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.

Article 36 - Consideration of reports

1. Each report shall be considered by the Committee, which shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The State Party may respond with any information it chooses to the Committee. The Committee may request further information from States Parties relevant to the implementation of the present Convention.
2. If a State Party is significantly overdue in the submission of a report, the Committee may notify the State Party concerned of the need to examine the implementation of the present Convention in that State Party, on the basis of reliable information available to the Committee, if the relevant report is not submitted within three months following the notification. The Committee shall invite the State Party concerned to participate in such examination. Should the State Party respond by submitting the relevant report, the provisions of paragraph 1 of this article will apply.
3. The Secretary-General of the United Nations shall make available the reports to all States Parties.
4. States Parties shall make their reports widely available to the public in their own countries and facilitate access to the suggestions and general recommendations relating to these reports.
5. The Committee shall transmit, as it may consider appropriate, to the specialized agencies, funds and programmes of the United Nations, and other competent bodies, reports from States Parties in order to address a request or indication of a need for technical advice or assistance contained therein, along with the Committee's observations and recommendations, if any, on these requests or indications.

Article 37 - Cooperation between States Parties and the Committee

1. Each State Party shall cooperate with the Committee and assist its members in the fulfilment of their mandate.
2. In its relationship with States Parties, the Committee shall give due consideration to ways and means of enhancing national capacities for the implementation of the present Convention, including through international cooperation.

Article 38 - Relationship of the Committee with other bodies

In order to foster the effective implementation of the present Convention and to encourage international cooperation in the field covered by the present Convention:

1. The specialized agencies and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialized agencies and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite specialized agencies and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities;
2. The Committee, as it discharges its mandate, shall consult, as appropriate, other relevant bodies instituted by international human rights treaties, with a view to ensuring the consistency of their respective reporting guidelines, suggestions and general recommendations, and avoiding duplication and overlap in the performance of their functions.

Article 39 - Report of the Committee

The Committee shall report every two years to the General Assembly and to the Economic and Social Council on its activities, and may make suggestions and general recommendations based on the examination of reports and information received from the States Parties. Such suggestions and general recommendations shall be included in the report of the Committee together with comments, if any, from States Parties.

Article 40 - Conference of States Parties

1. The States Parties shall meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present Convention.
2. No later than six months after the entry into force of the present Convention, the Conference of the States Parties shall be convened by the Secretary-General of the United Nations. The subsequent meetings shall be convened by the Secretary-General of the United Nations biennially or upon the decision of the Conference of States Parties.

Article 41 - Depositary

The Secretary-General of the United Nations shall be the depositary of the present Convention.

Article 42 - Signature

The present Convention shall be open for signature by all States and by regional integration organizations at United Nations Headquarters in New York as of 30 March 2007.

Article 43 - Consent to be bound

The present Convention shall be subject to ratification by signatory States and to formal confirmation by signatory regional integration organizations. It shall be open for accession by any State or regional integration organization which has not signed the Convention.

Article 44 - Regional integration organization

1. "Regional integration organization" shall mean an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by this Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by this Convention. Subsequently, they shall inform the depositary of any substantial modification in the extent of their competence.
2. References to "States Parties" in the present Convention shall apply to such organizations within the limits of their competence.
3. For the purposes of article 45, paragraph 1, and article 47, paragraphs 2 and 3, any instrument deposited by a regional integration organization shall not be counted.
4. Regional integration organizations, in matters within their competence, may exercise their right to vote in the Conference of States Parties, with a number of votes equal to the number of their member States that are Parties to this Convention. Such an organization shall not exercise its right to vote if any of its member States exercises its right, and vice versa.

Article 45 - Entry into force

1. The present Convention shall enter into force on the thirtieth day after the deposit of the twentieth instrument of ratification or accession.
2. For each State or regional integration organization ratifying, formally confirming or acceding to the Convention after the deposit of the twentieth such instrument, the Convention shall enter into force on the thirtieth day after the deposit of its own such instrument.

Article 46 - Reservations

1. Reservations incompatible with the object and purpose of the present Convention shall not be permitted.

2. Reservations may be withdrawn at any time.

Article 47 - Amendments

1. Any State Party may propose an amendment to the present Convention and submit it to the Secretary-General of the United Nations. The Secretary-General shall communicate any proposed amendments to States Parties, with a request to be notified whether they favour a conference of States Parties for the purpose of considering and deciding upon the proposals. In the event that, within four months from the date of such communication, at least one third of the States Parties favour such a conference, the Secretary-General shall convene the conference under the auspices of the United Nations. Any amendment adopted by a majority of two thirds of the States Parties present and voting shall be submitted by the Secretary-General to the General Assembly for approval and thereafter to all States Parties for acceptance.

2. An amendment adopted and approved in accordance with paragraph 1 of this article shall enter into force on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment. Thereafter, the amendment shall enter into force for any State Party on the thirtieth day following the deposit of its own instrument of acceptance. An amendment shall be binding only on those States Parties which have accepted it.

3. If so decided by the Conference of States Parties by consensus, an amendment adopted and approved in accordance with paragraph 1 of this article which relates exclusively to articles 34, 38, 39 and 40 shall enter into force for all States Parties on the thirtieth day after the number of instruments of acceptance deposited reaches two thirds of the number of States Parties at the date of adoption of the amendment.

Article 48 - Denunciation

A State Party may denounce the present Convention by written notification to the Secretary-General of the United Nations. The denunciation shall become effective one year after the date of receipt of the notification by the Secretary-General.

Article 49 - Accessible format

The text of the present Convention shall be made available in accessible formats.

Article 50 - Authentic texts

The Arabic, Chinese, English, French, Russian and Spanish texts of the present Convention shall be equally authentic.

In witness thereof the undersigned plenipotentiaries, being duly authorized thereto by their respective Governments, have signed the present Convention.

APPENDIX C: A HEALTH EQUITY ASSESSMENT TOOL (EQUITY LENS) FOR TACKLING INEQUALITIES IN HEALTH

Date of publication: May 2004

There is considerable evidence, both internationally and in New Zealand, of significant inequalities in health between socioeconomic groups, ethnic groups, people living in different geographical regions and males and females (Acheson 1998; Howden-Chapman and Tobias 2000).

Research indicates that the poorer you are, the worse your health. In some countries with a colonial history, indigenous people have poorer health than others.

Reducing inequalities is a priority for government. The New Zealand Health Strategy acknowledges the need to address health inequalities as ‘a major priority requiring ongoing commitment across the sector’ (Minister of Health 2000).

Inequalities in health are unfair and unjust. They are also not natural; they are the result of social and economic policy and practices. Therefore, inequalities in health are avoidable (Woodward and Kawachi 2000).

The following set of questions has been developed to assist you to consider how particular inequalities in health have come about, and where the effective intervention points are to tackle them. They should be used in conjunction with the Ministry of Health’s Intervention Framework (PDF, opens in new window) (Ministry of Health 2002).

1. What health issue is the policy/programme trying to address?
2. What inequalities exist in this health area?
3. Who is most advantaged and how?
4. How did the inequality occur? (What are the mechanisms by which this inequality was created, is maintained or increased?)
5. What are the determinants of this inequality?
6. How will you address the Treaty of Waitangi in the context of the New Zealand Public Health and Disability Act 2000?
7. Where/how will you intervene to tackle this issue? Use the Ministry of Health Intervention

Framework to guide your thinking.

8. How could this intervention affect health inequalities?
9. Who will benefit most?
10. What might the unintended consequences be?
11. What will you do to make sure it does reduce/eliminate inequalities?
12. How will you know if inequalities have been reduced/eliminated?

(Adapted from Bro Taf Authority. 2000. Planning for Positive Impact: Health inequalities impact assessment tool. Cardiff: Bro Taf Authority.)

Amended by Ministry of Health. May 2004.

Retrieved from <http://www.moh.govt.nz/moh.nsf/pagesmh/3968>

APPENDIX D: QUESTIONS FOR HIA PRACTITIONERS

1. Can you please tell me about an HIA that has been really valuable, and why this was?
2. Can you please tell me about an HIA that has not gone well and why this was?
3. Do you feel that the way HIA is carried out is the way it was envisaged to be by those who wrote the policy guidelines? Why/Why not?
4. Can you please tell me what kind of process you go through to identify groups who need to be thought about in an HIA?
5. If for instance you were doing an HIA on a swimming pool facility, what would some of the main issues be that you would ideally think about?
6. Is this ideal situation, what would happen in everyday practice?
7. What are some of the constraints that limit how much of the population you can think about?
8. Given these many constraints what kind of process do you go through when deciding what issues to focus on?
9. Do you see any other barriers that prevent the optimal use of HIA?
10. In the development of the swimming pool Scenario that we have talked about, what issues would be pertinent to you regarding people with disabilities?
11. Do you always assess people with disabilities in your practice?? Why/Why not?
12. Do you feel that when they are left out of practice it is for legitimate reasons?
13. Can you think of any barriers that make it hard to include people with disabilities into your HIA practice?
14. If you could change one thing to increase the affectivity of the HIA what would it be?

APPENDIX E: INTERVIEW QUESTIONS FOR HIA POLICY MAKERS

1. Richard Morgan's article "Institutionalising HIA- the New Zealand Experience", describes the way that the first HIAs performed in New Zealand followed a very EIA focus and nature. In your view why do you think this is, and what do you think has changed in the present 2005 'Guide to HIA' toolkit?
I guess these newest guidelines have taken a more people focus- especially focusing on disadvantaged populations and how they can be beneficial in the HIA process.
2. When you were writing these guidelines, what considerations were uppermost in your mind?
3. When you were writing the guidelines, how did you take account of disadvantaged groups? What specific issues did you think would be pertinent to them?
4. Is your policy practiced the way you envisaged it being?
5. What barriers do you see in the HIA policy being implemented?
6. Are you familiar with the social and medical models of disability?
7. Which model did you have in mind when writing the guidelines that provided assessment for people with disabilities?
You have written very inclusive guidelines to understand the barriers that people with disabilities face in society.
8. What process did you go through to understand the barriers that people with disabilities face?
9. Do you think that it is important that HIA practitioners performing the HIA's, also have this understanding of the barriers that people with disability face?
10. Do you feel that differing understandings of disability may hinder the process of HIA?
11. There have been many other reasons cited in the literature about generic barriers to HIA practice including resourcing, peoples understanding of what an HIA is, government commitment etc. (Signal et al, 2008). Do you see any of these reasons as a hinderance to disability inclusion in HIA?
12. Do you see any other reasons why disability may not be optimally assessed in the HIA process?

APPENDIX F: NARRATIVE WITH INTERVIEWEE A

Interviewee A has been working in the HIA field for ‘about three years’. The HIAs that he has worked on are. ‘...one in Papakura in a housing development, one in Auckland region looking at the transport strategy, one in Manakau city looking at the long term urban planning for the city centre area, another one in Manakau looking at the long term planning for Wiri which is a suburb adjoining the city centre. [I have] supported Waikato DHB in running an HIA on the regional transport strategy, and we’ve supported environment Canterbury regarding an HIA they have been leading working with community and public health there as well.. Of these he feels the ‘Manakau built form and spatial structure plan HIA’ has been the most successful He explained that this was because ‘...it has gone right through the policy process, and it was able to inform elements of planning in the ...city centre. The HIA itself was looking at the, sort of long term plan for the city built environment would look like over 50 years. So it is a very, very long-term thing. We didn’t change the plan much because it is already written, but it is helping them form the ongoing development of other plans in the area like the public domain manual. Overall it was successful as it was the first HIA that had been done in Manakau for a while, and it had very good stakeholder engagement across the Maori and mainstream...well we got wide ranging input into in once we had drafted it and we actually had a debate at a full council meeting...and then a council vote on whether it was endorsed or not.’

Interviewee A expressed that he has ‘big reservations’ about the ‘purple books’ that the HIA guidelines are presented in. ‘I think it’s very good at laying out the bases you need to cover- in terms of identifying impacts, and it is very, very detailed approach to doing that. Where I think its shortcomings are, are in two areas: one, it is a very poor engagement tool. It gives you lots of tables to fill out, but as an experienced facilitator; I would never put a bunch of tables in front of people and say, fill these out. And we’ll call it an HIA. A consultation process needs to be much more conversational, much more engagement oriented than getting people to sit in a circle and fill in bug tables. The other reservation I have with the purple guide is that- and this sounds a little bit sad to say, is that it is very impact focused- which is fine as far as it goes- it is important to identify the impacts, and it does that very well, but it is very poor at solutions. If you go through all the tables and all the pages of the purple book, you will find there is one column, and one columns only which says ‘solutions to the issue’, and that is no way to consult. Putting it bluntly if people running HIA’s don’t put almost as much focus, as much attention as they do on impacts, then they are just going to be sitting on the sidelines, throwing stones, and not actually being part of making something change.’

Interviewee A feels that his team have had to ‘...buil[d] in quite comprehensively the engagement process- working with the people, not just identifying impacts but also identifying solutions, and to do that we’ve had to go outside the purple books, we’ve had to bring in facilitation techniques that engage people much more conversationally, draws out their input much more in different ways, and we think it produces more a more forward looking HIA...’

Interviewee A identifies that the population groups that need to be focused on in an HIA 'usually come out of the scoping phase', [where we ask the stakeholders] who are the populations who are most likely to be most affected, and who we need to involve in the subsequent stages of consultations.... I have not done an HIA where there has been any surprises in terms of the populations [have been identified], and you know it is usually Maori, Pacific, low income, people with disabilities sometimes refugee and migrant populations and sometimes rural populations, depending on what the issue is. So Sometimes these people are identified and in subsequent stages we try to ensure that people who in some ways represent those communities are involved in the HIA.

When talking about a hypothetical example of a swimming pool, Interviewee A identified accessibility as one of the most important issues. He explained 'how easy it is to get to, and are there any cost barriers to people getting there- so yeah, physical access and financial access...then there is also location in terms of getting across the car park. For a person with a disability's point of view, you'd look at how easy it is to get in there, what age the facilities like for people with disabilities, what age the services like for people with disabilities, what are the services that might be provided for different population groups as well.' He cites the example of how in Auckland they provide Muslim Woman's swim classes, where Muslim Woman can go along with the benefit of a pool which is closed off to men, and culturally sensitive for that sector of society. He points out he would be thinking '...likewise what services could be available for other population groups, and I can imagine people with disabilities have an interest there.'

But he admits that though the issues he has raised are 'best practice, they are not reality. '...if you go to the Olympic Swimming Pool in Newmarket, you have to go down steps to start with... so no.' He explains that '...a lot of the new construction in any public facility has to have disabled persons access built in, and that is certainly in terms of the physical construction, whether or not it goes so far as to be able to ensure that everyone with different types of disability are able to use it functionally is another matter. Things like, particularly for people with visual disabilities, we haven't gone down the path of public facilities, like you know talking bus stops or things that you can easily feel your way through...I think standards have moved further down the track to be able to incorporate people with disabilities a lot more. I think there are probably still issues that can be challenged.'

Interviewee A feels that the HIA Process has little interest for 'engaging people with disabilities on the whole.' He feels that these barriers are part of the generic barriers to HIA- 'I think the barriers to disability being considered in HIA is probably more about the barriers such as full stop.'

Interviewee A points out that many of the generic barriers to HIA stem from the cuts to the MOH HIA support fund. '...unless DHB's in particular and to a lesser degree local government decide there is a usefulness for them in doing this sort of thing, then we won't see as many HIA's being undertaken in the next few years.'

Interviewee A can only remember one HIA project he worked on where there was no input from someone in the disability sector. When explaining why this was, Interviewee A explained that ‘...we put out invitations for people to come...or it was suggested we get people to....’ But obviously they didn’t come. In all the other HIA projects that Interviewee A has worked on, he feels that disability assessment has been taken out with the ‘best intentions.’ He does however feel that ‘I don’t think it is always done as well as it could be.’ He rationalises this by the generic barriers of ‘time and money’ which are constraints for all HIA’s in the New Zealand experience. ‘...the time pressures and the resource pressures, for people running them, they just think, let’s get everyone into a room and get this concentration done and try and cover all the perspectives. If we had all the time resources, it would be, I think it would be, particularly from a disability perspective, it would be great to have a fixed discussion with a group of people that concentrated on those issues. And also there is not the same competition for the voices to be heard [in the scoping meeting].’

He also points out that, ‘Also there is not the same accessibility to resources, in terms of people with visual disabilities needing to be told what is in the current powerpoint slide.’ He feels that ‘actually being able to have a discussion that meets their needs in a way that a mainstream discussion can’t’ [would be very beneficial].

Interviewee A also feels that people with disabilities have to make their needs obvious to HIA Practitioners. ‘...sometimes you need to be told directly, this format doesn’t work too well for me, could we try it differently...’

He goes on to explain the way that Maori consultation is almost a mandatory part of HIA practice. He said this is because if ‘funding criteria for the HIA says that you must run a whānau ora workshop then that automatically setting in a prioritisation that you will automatically have a dedicated Maori consultation workshop...it is often a given that Maori want to be consulted on their own terms in their own patch....do people think of lets actually run a disabilities specific workshop?’

In his explanation to why there are not disability-specific workshops run, Interviewee A returns to his explanations of ‘time and money.’ He explains that there are a lot of populations to scope and the HIA practitioner must ‘try and get as many different groups of people as possible...because you are not just trying to get people with disabilities in the room...so you’ve got multiple interests you want to get into the room, and disabilities is one of them, and often it is just the straight line to the goal, just invite them all at once rather than thinking about actually ‘who are the ones we might need to consult with in a different way?’

Interviewee A then talks of an evaluation he is doing on a specific disability project, and that ‘one thing we learned very quickly is that people with disabilities needed to be engaged one on one...that works better and you actually you do get a much more....a much richer view from that.’

APPENDIX G: NARRATIVE WITH INTERVIEWEE B

Interviewee B was very interested in the HIA because of the ‘... policy level and looking at the media awareness that a lot of what effects people’s health comes from other sectors like education, housing, employment, the economy etc. So I was really interested in that as sort of a real way to improve things. She felt the greatest way to change things ‘in reality’ was at policy level. She said that the first facet of social determinants she worked with was transport. This is because she was doing work in the field of ‘transport and health’ and had already completed literature reviews around the area which had increased her understanding of the area. She said she was interested in ‘how they were trying to broaden the transport sector’. So there was a bit of move from the highest levels, like from the Minister down, to actually look at the public to actually look at the public health implications of transport and make that part of transport’s mandate, so it was actually quite an exciting time for us seeing that there was a bit of a shift happening...and supporting them to ask what does that actually mean if transport policy makers are required to consider health and well being more as part of their work and how they would do that. And we saw the HIA as a practical way of dealing with that.

Interviewee B feels that the differences between EIA and HIA is that the HIA is a lot broader and focuses on the determinants of health. ‘The earlier ones were linked with the legislative requirements to look at health as part of the RMA. So they were more focused around a narrow potential health impacts. , but looking at things like noise or vibration or air quality that sort of thing. She feels that the EIA guidelines are more linked to resource management processes, and that the HIA guidelines are ‘more about health and public policy and how can health be considered more fully in policy making.’

She feels these changes were ‘partly to do with international developments in that area...and a greater focus on health promotion in that area.’ She acknowledges that Healthy Public Policy was originally talked about in the Bangkok Charter [of Public Health] but feels that these changes really came about because people started thinking, ‘how can we have a greater focus on health in policies in other sectors outside of health.’ She points to some research that Richard Morgan supervised ‘which looked quite closely at examples of those previous guidelines being used along with the EIA process....looking at how effectively health had been considered.’ ‘And that research showed it wasn’t being fully considered in New Zealand- it was quite a narrow definition of health. And that would be another difference between the two sets of guidelines; the later guidelines had quite a holistic view of health.’

Interviewee B said that the aim that she wanted to project through the guidelines, to the practitioners who were performing HIA was the fact that it was ‘aimed at policies outside health.... and encourage a more explicit focus on health and wellbeing in the broader sense.’ Specifically Interviewee B felt that she thought ‘there was quite a bit of attention to Maori as a particular group that were potentially disadvantaged... and how should the guidelines include the treaty in terms of advice that people should be thinking about.’ ‘So they did include Maori and

Pacific people, but also groups like children and youth and older people....when we were thinking about transport there was quite an emphasis on cyclists and pedestrians as vulnerable road users compared to pedestrians in cars.And we also looked at people with disability who were potentially disadvantaged.'

Interviewee B talked of a project which was taking place at the same time as the HIA guidelines were being written. This was a project on people with intellectual disabilities. PHAC released a report based on the project called 'To have an ordinary life.' This report encouraged people to change from the medical to social model. She felt that this encouraged the conversation about disability within PHAC 'I think there was a lot of discussion around transport particularly and also urban design issues like how people with disabilities may have different needs in the urban environment like you know physical accessibility to buildings, footpaths, that kind of thing.' She also explained that this rhetoric philosophically ensured a broad health impact assessment that would also look at the needs of people with disability and how they would be involved in the process.' She felt this encouraged a 'wide range of experts in different areas, and that would include disabilities.'

Interviewee B felt that the practice of the policy that was written has been both successful and also not fully effective. She felt that 'there has been quite a growth in the HIA, which has been really, really encouraging.' She explained that for the past 5-6 years the amount of HIA's that have been completed has grown every year. And along with this growth, is the number of people who are doing the training workshops to learn how to do HIA. 'In some ways it has grown even faster than we envisaged...' She also stated that more HIA's were being done at Local level which was not envisaged as they 'were thinking more about HIA's happening at the Central level, so more the central policy agencies like housing or transport or education. I think our political vision was that there would be a lot more HIA's happening at that level.' She said it had become attractive to local councils as '...councils are looking at how they can ensure their work is improving the local community's wellbeing.' She also explained that it might be easier to do an HIA at a local level as it is easier to concentrate on a small defined population [as some of the central government policies are a lot more complex.]'

Interviewee B understands that other agencies apart from health may not have an explicit focus on wellbeing as they may 'have a lot of other considerations', but she feels 'an ideal would be if the HIA's were generated more from these other policy agencies, and that the health sector...would provide...would work in partnership with them to help it happen.'

However she feels that the specific practice of HIA is occurring as it was envisaged; in terms of more training, more resources and more support.' She feels the public health bill and legislative mandate on HIA are stalling the use of HIA, however she feels that 'given [these circumstances] it had grown really rapidly.' She said this take up has been most notable in 'Hawkes Bay, Auckland and Christchurch.'

She feels that the way these HIA's have been done has been positive with a '...' broad definition of health, and they have taken a reasonably inclusive approach.... [with] most of the workshops

including quite a range of people from different areas of expertise, and they've included community representation, and sometimes youth representation.'

Interviewee B feels that what is focused on in an HIA 'is quite dependant on who that is involved with it at the time.' If an HIA practitioner who has a good understanding of disability is performing the HIA, 'it might be that some of the ones where there have been more focus on that, it might just be that some of the individuals that are involved have got a stronger focus themselves on that.'

Interviewee B also explains that training could be one reason that there is not much emphasis put on disability in HIA, 'I'm not sure how much emphasis the training gives on disability in particular. It maybe that this is not covered in enough depth to equip people to focus on disability.' there is always quite big limitations of time and people, resources, money, and I think the reality is that the policy-makers are quite time-poor and they've got a lot of time pressures on them, Sometimes it is the issues you are looking at in the HIA's. I think sometimes that can be overwhelming in itself [which means people with disability are often not prioritized.]

Interviewee B also feels that the prioritization process is mostly dependant on the community in the scoping room. She finds it a challenge to '...get people to focus on one or two population groups....and one or two health determinants' as they often want to think about everything, but given the resources available for utilisation that would be impossible. She also feels that the 'issue' really influences the populations prioritized. 'This is controlled by the 'people needing to make the priorities depending on what they are looking at.'

Interviewee B feels that even when people with disability 'are not named as one of the population groups, they could still be included in the consideration [recommendations]. She explains this by using the example of 'The Urban Development Strategy', where people with disability were not named as one of the priority groups, but 'there were definitely times in the workshop where people raised those issues as being really important, in terms of having better access to services and having improvements to footpaths, and walking trails, and those kind of things...so there was consideration of physical disability there.'

Interviewee B feels that the differences between the social and medical models of disability is not particularly well understood. She feels that this could be a limitation to people seeing the scope to assess people with disabilities in their HIA practice. 'So maybe there needs to be a process of working with the other agencies to help them understand that disability is quite different to how they may think about it.' She concedes that HIA Practitioners would probably have quite a 'varied understanding' of these models too. She thinks this 'comes down to the guidance they've had access to, and yeah the training.'

APPENDIX H: NARRATIVE WITH INTERVIEWEE C

Interviewee C believes that a change came about to the HIA Guidelines when the 'National Health Committee' (the PHAC, Public Health Advisory Committee, commissioned work to prepare a manual or guideline on how to do HIA. The committee had formed a view that HIA was an important tool to be used and it would deliver better insight into activities in the policy making in the policy making arena than had been the case to that time.' Interviewee C recalls the first time they tried the HIA policy out, on the Ministry of Transit, '...we got from them an actual policy that was in development to trial the HIA methodology on.' He recounts what happened when an important colleague came on to the HIA scene in 2006. ... 'He returns from overseas, with all his international experience, and considerable international status, and we teamed up, and continued to promote by going to Agencies and telling them about HIA.'

Interviewee C attributes his background to the way he thinks about 'disadvantaged groups' in the HIA. He states that he is not a 'public health person' and his experience comes from being a 'methodologist, coming from environmental affects assessment, and related areas and social assessment'. When defining how he understood the principals of the HIA, he reflected, 'When I was thinking about disadvantaged people or groups, , the thing that would come to my mind is those with physical disability...what I learnt from the public health people that I was working with, and it was important learning for me, was around the inequalities between population groups particularly the Māori and Pacifica, and with the migrant groups tend to report more in various disadvantaged categories in society.

Interviewee C feels that he was not the person to understand the issues that every disadvantaged group faced, 'I wasn't the person briefed to bring that particular knowledge to the guideline.' Instead he explained that as his position as a 'social democrat', he had a strong focus on redistribution of income. The people who he feels are disadvantaged, are the people who do not have access to that money. He feels that 'If you can overcome the money barrier, then the people...are more enriched , have got the means to address all the issues.'

As a practitioner, Interviewee C felt it was his responsibility to understand the specific limitations that every assessed population group faced. He feels the guidelines provide a 'mapping process, and it is 'within the process of each individual HIA that you start to [understand the limitations that each particular population group faces]. He wonders if 'the guide should provide particular cues or flags [to remind the HIA practitioner to think about populations such as those with disability].

He feels that the HIA policy guidelines are not practiced the way they were envisaged to be. He states that it was prepared to be used mostly by central government, '...and it has been used mostly by local government. And it has been used mostly around what we would call planning rather than policy making... policy makers are not interested in it much.' He goes on to explain that the reasons for this stem from the negated hypothesis that the 'Ministry of Social Development would be eager to take up the HIA process in its proceedings....as they are looking

to assist people who are disadvantaged in various ways. And though there were a couple of Champions who we had identified who understood HIA and thought it was quite a good tool, the policy making arrangement that MSD had in place was so firmly established and so well thought of internally that they saw no reason to introduce other tools or routines.’

As Interviewee C comes from a general methodological background and not a specific HIA history, he didn’t have ‘any particular anticipation or expectation at the time’ [the HIA Guidelines were written]. So he does not really have an opinion as to whether he feels that the practice of the HIA policy is carried out.

He does however think that one reason why the institutionalization of the HIA has been so difficult is because the methodology was ‘so foreign to those involved in policy making’. ‘All our HIA’s involve consultation with small groups, or large groups sometimes with focus groups as well. Government Departments are not used to doing this in early days of their policy development. They are used to developing policy using their own resources. And their own knowledge, and when the policy is made it may be given out for comment and consultation, so the process itself was a challenge to the way they do things....In some way some people in the MSD felt that taking the opinions of the people was a less rigorous process...they didn’t think it was evidence based....Well we had a breakthrough, what is this eight or nine years down the track...the Ministry of health has finally made a commitment HIA and running training courses internally...’

When describing a ‘successful’ HIA, Interviewee C referred to the ‘Hawkes Bay, Graffiti Strategy’ HIA. He explained that he felt it was successful because it brought together both the taggers and the mother’s and solo parents, and facilitated an engagement process, which allowed the taggers to understand that the community found their ‘big graffiti drawing, and tagging intimidating...and once the gaffers (taggers) realised that, some of them started to change their behaviour.’

When the topic of the social model of disability arose, Interviewee C recalled a story that his wife (former Minister of Disability) told about a conference ‘... there was a speaker with some disadvantage, I don’t know whether it was visual or aural, ...but anyway she was on stage, and said, stand up if you needed the venue to provide you with a chair, and she said, stay standing if you needed the lights that are provided by the venue...she was isolating those who were without disability, making the point that they were in their own way putting a demand on the facilities....if there was a model in any way or a reference point [while writing the guidelines], it was that there are inequalities in society and policy makers are not recognising them as much as possible and this tool can help them understand what these inequalities are...and lead them to a position where they can start to address them....you can have the clear idea in your head that you’re addressing inequalities but be blind to some sorts of inequality. Unless you begin to be quite explicit about the nature of the inequality that you are seeking to address. Then people with disabilities may well not be addressed at all.’

Interviewee C, and his colleague conduct training courses of the HIA tool throughout New Zealand. Interviewee C feels that ‘if you follow the guide to the letter...you start amassing a huge amount of... well basically a huge number of questions. You get to a point where you have more data than you can possibly get to a level of quality or confidence, that it would be helpful to get.’ Interviewee C explains, that the New Zealand version of the HIA model, means that Māori, and Pacific peoples are always prioritised in any HIA. He goes on to explain that older people, young children, and low socio economic peoples are next in line to be prioritised. He says that even before the scoping process has been completed ‘they’ve already decided what groups they want to concentrate on, and often disability aren’t one of those groups.

He also talks about people with disability being pertinent in some HIA’s, The Greater Wellington Transport Strategy, and the Avondale one...were concerned with people with mobility challenges, and that is probably as close to defining or identifying a group with a specific disability as we got. Interviewee C admits that in the training there is not a lot of emphasis on disability, and he feels that after undergoing this interview he will change the way he does things when he conducts his next training.

Interviewee C gives a rundown of the HIA Practitioners in New Zealand, and their fields of interest and experience: one ‘is a dietician and passionate about health and wellbeing around food, exercise and quality of life, Maurice Matis is a Māori Woman whose passion is around inequalities to do with Māori...’ He does this to explain that each HIA practitioner ‘approaches the HIA and the weight and value we give to different elements we give in any population that maybe subject to a project, that is subject to an HIA- that’d be more influenced by your life experiences and our formal training and our basic training.’

Interviewee C identified a process that he would go through when undertaking an HIA on a swimming Pool Complex. He states that ‘It is the Practitioners job to ensure that that the process is populated with the ‘right’ people and the ‘right’ information and the right has inverted commas around it because ‘right’ is qualified by time and money. ...Will issues with disability get into that process? I think the fullest answer is only if they are glaringly obvious but the challenge is to think about what might be glaringly obvious.

Interviewee C repeats that he is ‘passionate and concerned about income inequalities in society because of [his] social activism background around inequalities.’ He explains his sensitivity to people with hearing impairments is because his wife ‘specializes in...the deaf community...she did a lot of work with bringing the cochlea implant money.’

Interviewee C talked of the money and resources and time constraints that define the New Zealand experience of HIA are a limitation for Disability to receive adequate consideration in HIA Practice. He feels that the ‘20 or 30000 dollars it costs to do an HIA immediately [put] concerns on what you can do. Interviewee C also feels that within the scoping process, the complexity of the issue makes it difficult to be inclusive of all effected groups. He talks about a maximum of ‘three or four population groups across three or four determinants.’ And people can only really answer 12 or so questions before they lose their concentration.

He also stated that people with disability are often not 'defined as a particular group' in the recommendations of an HIA report, but maybe included under a label 'for those who mobility is a challenge'. In this population group you get mothers with prams, you get older people with walking frames, you get people on crutches, you get all the people who've got all the mobility challenges. He explains that although the specific label of disability is not defined, 'you've got some representation of their issues, and that's generally how we manage to squeeze the money in a marmite way...'. He acknowledges that this method is 'a copout. Because people with disabilities are not recognised, they are not on the page, they are not on the table necessarily.'

He thinks about this point and feels that the reason disability is not on the agenda 'is the same in all policy really. Unless there is some requirement by legislation, some requirement by organisational...agreement or by representation in the groups that are doing it, then they are left on the outside.'

Interviewee C concludes the interview by agreeing that the HIA can make the world more inclusive for people with disabilities. He thinks that 'Funding needs awareness', and feels this is largely a characteristic of the present government.

APPENDIX I: NARRATIVE WITH INTERVIEWEE D

Interviewee D feels that the differences between Environmental Impact Assessment and Health Impact Assessment are that an EIA is more of a risk analysis and it has taken a while for people to move to a more strategic approach. She felt the HIA takes a much more people focus, 'I don't know a lot about the EIA, but I just know we wanted a much more holistic approach...and a much more people focus.;

When writing the guidelines, Interviewee D explained that what she really wanted to get across was the 'importance of ensuring that potential for effect o health and wellbeing as a population, as the population-level was well thought through and assessed before policies were implemented.' She explained that another key focus was equity and that '...the work that had been already done on the health equity lens was drawn on for that reason.'

She also identified that there were groups 'who fall behind in health and wellbeing indicators and policies must be assessed for impact on those groups for implementation.' She also agreed that people with disabilities were one of those groups, but stated that when they wrote the guidelines, they deliberately wrote them in a generic manner so because they 'wanted them to be used in different situations.' She said that they tried to write the guidelines so they could be population-based, or issue-based, and though there were not specific questions for specific populations written in the guidelines, but 'woven through the guideline, were questions areas that we were trying to focus the reader or the planner on equity issues...and you can see a lot of the tables [define]the things you have to be considering for special groups within the population, all the way through the process.' She said that '...the expectation would be that the practitioner would have collected all of the relevant information [in the scoping process].' She went on to explain that the process that needs to be undergone so that the HIA practitioners understand the issues 'That are pertinent to a particular group, comes from the 'participation of the group you are focusing on in particular [in the scoping meeting]'. She also explained that 'participation' has been emphasised right through the guide.

Interviewee D pointed out that it is actually not possible to include every important issue when you are doing an HIA...[unless] you have two years', but you often don't,... as you are having to work to council or government deadlines. You don't have the luxury of time.' She used the example of the Greater Urban Development Strategy headed by Anna Stevenson, to explain the way that at the scoping meetings decisions had to be made about what was in and what was out....pretty drastic cuts have to be made at times.' Interviewee D acknowledged that 20% of the population reporting to having a long term disability was a high proportion and that she agreed that they should be included in every HIA performed.

However she explained that it was not the HIA practitioner who always had control of that process, as 'they don't ever own any of those HIA's.' She explained that you cannot actually tell local governments what they should be focusing on.'

She cited Wiley and Mulgrews paper which identified that ‘...cost was a big barrier and also lack of capacity ‘which she felt was increasing as demonstrated by the downsizing of public policy agencies and the health impact assessment unit itself. She felt that HIA was in ‘jeopardy’.... and felt that it would be a ‘miracle if it survives actually.’

She explained that in doing HIA’s, she found that local government was much more likely to pick up on HIA than central government, and that ‘we didn’t have too much luck with them at all.’ She explained that ‘a lot of it was confidence as well, and the training we put on in the summer school ...and you know the elementary course gave you the basics, but people needed to be doing it in teams to really learn.’ Separate to cost, lack of capacity, and lack of confidence, she also explained that another barrier was that ‘some government departments thought they were doing it sufficiently well already... [but they] basically weren’t’. ‘Politically driven policy’ was another barrier that Interviewee D identified, using the example of the cutting of social welfare benefits in the nineties and the effect this had on health and wellbeing.

When asked if the HIA policy was practiced the way it was envisaged to be, she explained that they ‘had hoped for more.’ She explained that though there was political support for HIA at the Chief Executive at Central Government Agencies, that often ‘at the end of the day, it was up to the analysts, further down the tree, and if they didn’t have time it was just set aside, basically.’ She agreed that without understanding the HIA, it is hard to see value in it, but in order to understand it, you have to give it time. She explained that there were many forms of HIA which could be used, which did not need the resources, time and capacity which was advocated for in the Guidelines they had written such as ‘you bring everyone in a room together for a day to work through it, and then it is written up. But you can even do it as a desktop exercise. We weren’t really advocating that because of the lack of participation...but it is possible to get somewhere,’ She also agreed that this could be dangerous as it could be a reason why specific populations may not be thought about.

Interviewee D stated that the generic barriers like ‘time and cost and lack of capacity’ are what sometimes limit people with disabilities being included in HIA practice. But she also explained that ‘when you come down to population groups it must be a lack of understanding as well because you need a certain amount of understanding to be concerned enough to say well we’ve got to actually be sure that we’re on the right path here, otherwise we’re going to impact adversely on this group...’

She also talked about the need for policy makers to have an understanding of the groups they are dealing with to even think that an HIA was needed...’

She agreed with one interviewee, that the training programmes that run could take a specific awareness to disability and this may increase the disability inclusion in HIA practice.

Interviewee D feels that the reason people with disabilities are sometimes not prioritised when there are limited resources is due to the views of people who have commissioned the HIA as they have control of how much resource is allocated to the HIA, or the external practitioners as ‘they can make the suggestions’ about what needs to be assessed.

One solution to increasing the prioritisation of people with disability in HIA are to, create a specific disability HIA, but Interviewee D is 'not sure if that would be the best way to go. In some ways it is more important to weave the focus into all the HIAs, [so disability is a part of every HIA performed as opposed to only when using the tool'

Interviewee D thinks the consideration of minority groups is often neglected in all policy, as is in HIA. She does however acknowledge that this should be less likely in the HIA due to its equity focus. She feels that 'if the scoping process worked or the information collecting stage is done well' then the inclusion of people with disabilities would always be present. Interviewee D feels this issue is a 'social problem caused by a lack of social awareness', and she is 'not sure what the solution to that is.'

She does however feel that the HIA is analogous to the social model of disability. She thinks this makes it a very valuable tool to be used to highlight the limitations that policy places on people with disabilities. She also highlights the need for a supportive 'government of the day.' She points to Britain as a model for 'social issues... who had a labour government for 12, 13 years'. She feels that this is part of the reason that both disability, and HIA have been so well taken up there.

APPENDIX J: NARRATIVE WITH INTERVIEWEE E

Interviewee E feels that the Wairoa Waste Management HIA which he completed with the Hawkes Bay District Health Board was one of the most memorable HIA's he worked on. This is because 'One of the big measures of the test of whether or not the decision makers change their mind, and take on the recommendations of the HIA- and ideally there being some sort of evidence that that is being implemented....' and this happened in the Wairoa Waste Management Strategy HIA. He feels that when an HIA is more than just a process, and is actually a decision making tool, it can be deemed a success. He recalls that 'in that particular HIA the recommendations were taken on board by the decision makers and by the regional council.' He also talked about the way that the recommendations that were arrived at due to the HIA process, were 'radically different to theoriginal proposal, and so it was a big shift in the way the council were thinking...

He talked of the Central Plains Water Strategy, as an HIA which did not come to as much fruition as he hoped. And he said this was due to the 'effect it had on the decision makers...I personally don't believe it had much of an effect on the decision makers.' Interviewee E did however feel that there were parts of the process of the HIA that went well, namely, '...they got some really good information, they had really good experts on board, and parts of it they talked to good parts of the community...the report was well thought through, and well argued...but when they actually got to the point of getting that information across to the decision makers, the wrong approach was used at that point, to the point that I doubt it had any...or very little impact on the decision makers.

Interviewee E expressed that he felt HIA was not being carried out the way it was envisaged to be. He explained that this was because 'the HIA guidelines were written by people in New Zealand who had never done an HIA. They were advised largely by professors at universities...who have been involved in large HIAs....so they've written the New Zealand guidelines from the perspective of a comprehensive all-singing, all dancing HIA. They've got [many] different questions you can ask about one intervention, and that is just far, far, far too detailed for the situations that we find ourselves in, in New Zealand.' Interviewee E also expressed his dissatisfaction with the way the guide was written, calling it 'content-focused'. He explained that 'the guides were sort of like, 'this is a good question to ask', rather than 'how do you ask it?'

Interviewee E feels that the HIA guidelines are very comprehensive, and 'tell you exactly which questions and how to ask them'. And when he began doing HIAs he realised that some of the questions in the guide didn't make sense for the particular HIA he was doing, and that the guide is 'just a guide- it is not the rules. You're allowed to get the gist from it, and then make it work for you...and that is sort of what we have done... and then tried to make it a bit more accessible for people in our daily practice.'

Though Interviewee E doesn't advocate using the guide to follow by letter, he feels that this was the thought, those who were writing it had at the time they composed the guidelines. He feels that putting people who had 'never done an HIA, and the people who had done [HIAs] overseas and done really, really comprehensive ones' was the reason that the guidelines were written which did not work for New Zealand [as we understand the capacity of HIA in New Zealand]. He feels that 'If we had another go at writing them now, it would be quite a different guideline.'

Interviewee E explained that 'the main way that we do it (an HIA)...is as part of the scoping meeting, when we are setting up the boundaries for the HIA. We go in and we basically ask the question 'how is this intervention (policy change) going to effect the local population? That is quite hard for the people to get their heads around because the local population could mean an old person, a young person, a Maori person, a person with disabilities it could mean a whānau.....we ask them to list all the potential groups, and usually you get a long list of about 10-15 groups... and then you say 'who are the groups you most know how this effects?...and we usually get them to prioritise three of them. And as a public health person, I try to make sure that [out of] the top groups that are covered that there should be At least one group in there that represents a vulnerable population, because otherwise the equity stuff won't come out on any level.'

He explains that 'prioritisation' is mostly influenced by the interests of the group present at the scoping meeting. He cites the example of the central plains HIA, where there were no people present at the meeting from the recreation industry. 'I could see that immediately as we did the rounds and I thought that there is no one from the recreation sector here, and that means when you scope it the chances of someone or a number of people arguing forcefully on the case for recreational users would be much reduced.' Interviewee E reports that when he identifies a gap such as the one described above, he personally tries to advocate on behalf of those groups. In that instance, I advocated quite hard for the recreation users...and in the end they were the focus of the HIA in Central Plains water.'

Interviewee E believes that it is his role to advocate for groups whose voices are not heard. 'So it is about trying to get a nice mix of types of population groups that you can analyse against, so you get a nice breadth of information coming back.'

Interviewee E also feels that prioritisation is influenced by the topic of the HIA. '...so if you are working on a transport topic, you are much more likely to be dealing with issues of access....and if you are considering issues of access, then people who have accessibility issues are much more likely to jump to the top of the queue as far as our focus goes for your work. [If you were doing an HIA] on Housing, low income people would naturally come up. So the topic does tend to influence the groups.

Interviewee E believes that while the 'people in the room' influence which groups are prioritised, his job as a practitioner is '...to facilitate an open ended discussion with those people...we have a small influence, but I would say that the scoping group in the room has the major influence.'

When given the hypothetical example of performing an HIA on a swimming pool facility, Interviewee E highlighted the issues of ‘access to the facility...is it on a bus route?, When you get there, are there parks for you if you are driving a car? Are there bike racks? And once you get through the doors, the centre what is the usability of that? So for example if you were an older person with failing eyesight, how big are the blinds. If you are a Mother, with a pushchair, are there barriers in the way? ...And then access within the centre, and to the resources within the centre. Price, affordability... so how affordable is it for people in that community?’ He comments that this is an ideal situation and if it were he would do an HIA on all the above factors he has mentioned, but in reality, the he does not know if the decision- makers would take on all the recommendations that he has made.

Interviewee E also acknowledges that he may not think of all the issues to deal with people with disabilities in relation to a swimming pool scenario as he is not familiar with the subject. He explained that ‘...that is where you would need really good advice from stakeholders who are experts in these things. It is not really the job of the HIA consultant to be the expert...we’re the facilitator not the font of all knowledge. When talking about people with disabilities accessing swimming pools, he talked of a friend who has a disability and is a wheelchair user. ‘...the Wellington Waterfront. He loves that, because there is a ramp, a concrete ramp that does straight into the sea. And he takes his old wheelchair down and he wheels it straight into the sea... So I would have thought a ramp would have been a solution to that conundrum.

Interviewee E explains that the scope of a ‘typical HIA’ is set by the decision makers. ‘So they decide who the priority groups are, they decide what the determinants of health and wellbeing are, so that they are getting answers to questions that they are really interested in’.

Interviewee E feels the main constraint that limits how much of the population can be assessed in an HIA, is ‘...How much a person can fit in their heads. How much time a person has got to give to us.’ He further explains that this is because each person is asked about the way that each population is going to be effected, and sometimes there are ‘10-12 different population groups, and your attention has waned and given up at about number 2. And then I go what are the potential negative effects?, what are the potential effects on equity? Are there any.... and there is another 7 or 8 questions I want to ask you....So part of it is just keeping my stakeholders on track, and one way you can do this is by, only [asking you] about people who you know well. But if I am going to be more specific, I need more time and more resources to be able to do that.’

Interviewee E does not feel that people with disability are an exclusive group. He feels that that they fit into many other groups who face similar barriers such as ‘old people, with poor eyesight and poor mobility, a young person who does not have access to a vehicle or drive a car, ...or a woman with a pram who has to try and get this large multi wheeled device around the streets. So there are some pretty big overlaps...’ Interviewee E also thinks that people are starting to realise that ‘if you make it easy for people to get around- if the signs are big and everyone else can see them, if it is wheelchair and pushchair friendly then it is just good for everybody. And one way you can do that is by talking [making recommendations] for people with disabilities.

Interviewee E feels part of his job is to push the 'universal design concept, 'to make it good for everybody, rather than just good for the white middle class males who are fully ambulatory.'

The other barriers that Interviewee E defines to the optimal use of HIA are 'often we got no or very little money, very little time, the people who are working with us have got a less than ideal skill set for undertaking the work, but we've actually got to get some information across to a decision maker and encourage them to change their mind, so most of our HIA's are pretty well scoped for the jobs that they are trying to do.'

'So the main barrier is access to appropriate information, to scope plan and undertake the HIA, because you know we keep telling people you can do this on the sniff of an oily rag, so I can't tell you it's money and I can't tell you it's time. I would love more time...I would ...always want more money. I will never be happy with the amount of money someone offers me for an HIA, and that would be great to have more time and money, but you've got to work within those parameters, and typically that means you've got to cut your costs.'

These pressures may limit the quality of the HIA and some population groups may not be assessed as well as they could be. Interviewee E feels that this is one of the things that we are not so good at in New Zealand '...fifteen priority groups get put up on the board. Because of the time and money and skill set we prioritised three of those...'

Interviewee E feels that when people with disabilities are part of the scoping meeting, they must make their needs known to the HIA practitioners. Their input maybe hindered if they cannot access the materials and they should make it known that they have alternative format needs, if they cannot use what is provided.'

Interviewee E feels that it is not appropriate to assess people with disabilities in every HIA as 'the priorities are set by the communities themselves.' He goes on to explain 'there will be plenty of situations where I was reviewing an HIA and I didn't see something about people with disabilities, I wouldn't especially be overly concerned about that, whereas there would be some where I would be...'

The only control HIA Practitioners have over the prioritisation process is around the scoping meeting. They can prompt people 'and sort of prick peoples consciences' if they are requiring that. So we have a small amount of influence I guess, but it is given a lot by the people in the scoping room themselves.

Interviewee E does not like to put emphasis on any one group in his training courses. However he does realise that there is a lot of emphasis put on Maori and Pacifica, and he puts this down to the obligation that New Zealand is bound to by the Treaty of Waitangi. He does not like to over emphasis any one groups because 'we've got to be really careful that we don't turn people off.' He draws attention to some work the Wood Johnson Foundation has been doing in the United States of America, about people's opinions of black minority ethnic groups. And they interviewed literally thousands of people about this subject, and came back with the conclusion that '...if you talk about black and minority ethnic groupsto anyone who isn't a black or minority

ethnic group, they shut down immediately and don't listen to anything else you say. And I think that sort of stuff is actually pretty transferable to the New Zealand population as well...'

Interviewee E does not feel that he can give an answer to the reason that people with disability are not always optimally assessed in policy, however he feels that lack of implementation when it comes to disability policy, that people don't actually care-is what it comes down to. He goes on to explain that the people at the top just follow 'the gaze of the public', and they dictate what gets implemented. He cites the New Zealand Transport strategy. 'The way the policy rhetoric at the front end talks about walking, cycling greenfields....and you'd think they were the most beautiful organisation under the sun....and they build roads, big roads, and lots of them....and they fund the building of roads with 70% of the money they have...' He thinks that this is only true in some cases in HIA as it '...depends who the practitioner is.' He feels that '...given the diversity of topics and issues that could potentially be the focus of an HIA, people with disabilities have got a lot of competition to get their nose in front- to be the population groups on the headlines.'

He feels that this is not adequately explained by a 'straight resource shortage'. 'When you look at your New Zealand HIA and the scope of the report, they will just about always have Maori at the top. How come Maori and people with disabilities are not? It is not always a resource issue, it is a decision. Prioritising decisions are being taken, and some people are being made the explicit focus of the study more often than others. And are there legitimate reasons for that? At the time of the scoping, I think people believe that is the case, but it is not a resource issue...' It is all the other things like who is in the room, what the topic is, the big issue in the community, the fact that we have got a Treaty of Waitangi...'

'At this point in New Zealand society, I think that Maori have got a priority because of the treaty, and because of the inequity they have suffered. So they take the best spot, pretty much every time. And as practitioners we have that drummed into us pretty much from the get go. If you work in New Zealand is a low income country, we have huge numbers of people in poverty....and a lot of the policy decisions that we're dealing with have big affordability issues to them, and I think the decision makers can see that, and they can sense it, and so they want to know how the decisions effect income-people on low income. So that is often high up there. So I guess what I am arguing is consciousness, aren't I?...it is how consciously aware they are of....need...the need to assess for that particular population group.'

'So based on what I have just said, I suppose it is about raising consciousness, because these things are hardwired, they're the things that people bring to every meeting that they go to...'

APPENDIX K: ETHICS APPROVAL

Ref: HEC 2010/66/LR

1 September 2010

Neelusha Memon

Social Work & Human Services Programme

UNIVERSITY OF CANTERBURY

Dear Neelusha

Thank you for forwarding to the Human Ethics Committee a copy of the low risk application you have recently made for your research proposal "Integration of disability into health impact assessment".

I am pleased to advise that this application has been reviewed and I confirm support of the Department's approval for this project.

However, this approval is subject to the following:

- Please forward a copy of the consent form and information sheet for HEC records.
- Please ensure that these forms are on UC letterhead and include the following:
 - Participants can withdraw participation and information at any time;
 - They will be able to review the transcript of the interview;
 - Include the supervisor's name and contact details;
 - An MA is a public document via the UC library database.
 - The project has been reviewed and approved by the UC HEC low risk process.
 - Details on data storage and that data will be destroyed after five years.

With best wishes for your project.

Yours sincerely

Dr Michael Grimshaw

Chair, Human Ethics Committee

